

Globalization and the Networks of Expertise in Turkey: The Politics of Autism

Emine Öncüler

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ABSTRACT

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Emine Öncüler Yayalar

This dissertation uses the case of autism to examine the changing contours of disability, personhood and civil society in contemporary Turkey. Drawing on qualitative data collected through fieldwork and interviews, I show that despite the arguments proposed by parents groups and the scientific literature, the dissemination of autism diagnoses globally does not indicate a universalization of the experience, interpretation and moral understanding of the disease category. Instead, the translation of autism to the Turkish context was contingent upon the specific institutional conditions determined by professional struggles, the organization of civil society and the transformation of the welfare state. My findings suggest that there is a split moral career of the child presenting with developmental problems in Turkey with divergent paths to referral, diagnosis, treatment and prognosis. In the absence of high quality, state subsidized special education services, middle class parents have allied with Western educated experts to disassemble the autism spectrum resulting in the formation of what I call a “disorder without a diagnosis”. These findings are significant in understanding the changing relations of expertise in a non-Western context.

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Introduction

If you were to visit Istanbul in 2006, you would get the impression that autism had become a major issue in the social and political landscape of Turkey. Autism was simply everywhere: on television, in the newspapers, in the bookstores, at the bus stops, on the billboards. The newly founded autism organization, TOHUM Foundation had mounted an effective public awareness campaign the previous year while the state had adopted a new legislation on Special Education making early intervention compulsory for children with developmental delays. Schools and centers serving children exhibiting symptoms of autism were multiplying throughout the city. While you would get blank stares if you mentioned autism in public circles a couple of years back, now everyone had an opinion about it or knew someone who was possibly autistic. Experts published warnings calling parents to get their children checked if they showed any kind of delay in language or communication. Autism checklists were translated and adopted to Turkish and health care providers received trainings in how to recognize developmental disorders.

While these developments resembled what was taking place in the rest of the world, a quick glance at the figures would show that Turkey was far from experiencing an “autism epidemic”. Statistics on autism diagnoses are hard to come by in Turkey since there is no official database where all the records are collected. However, data on special education statistics could give us some clues on the observed prevalence of autism in

Turkey. According to data collected by the Ministry of National Education, of all the students enrolled in special education and inclusive education classrooms in the 2010-2011 school year, 1,593 students were placed in autism only classrooms out of a total of 141,248 students receiving special education between the ages of three and fourteen. This is approximately 1.1 percent of the total number of students receiving special education (MEB 2011). For a more accurate figure, we can refer to data collected by the Guidance and Research Centers, which provide evaluation and support services for students with special needs. In 2009, there were 10,811 children who had received a diagnosis of autism at these centers out of a total number of 326,423 children, which amounts to only 3.3 percent of children evaluated at these centers. (Tohum Otizm Vakfi 2010b: 15)¹. Compared to figures in the West, these numbers are insignificant. For example, data from recent studies suggest that 1 in 110 children in the United States are on the autism spectrum.

According to autism experts, this discrepancy could easily be explained by resorting to a theory of underdiagnosis. One could argue that as autism awareness and methods of detection expand, more children will get the diagnosis, which in turn will result in parents demanding better services. This impetus will then create new markets for autism therapies as the state begins to sponsor interventions for children with developmental delays. In fact, this was the theory on the expansion of autism that I encountered the most in the field. The professionals working with children on the spectrum as well as parents were faced with a dilemma. They had read about the “autism

¹ The total number of children between the ages of five and fourteen residing in Turkey in 2010 were 12,699,869 which is 17.2 percent of the total population. (Turkish Statistical Institute 2011)

epidemic” in the West, yet the numbers in Turkey did not come close to anything observed in other parts of the world. Where were these children? Maybe they had received other diagnoses like mental retardation or attention deficit disorder? “This is not a case of misdiagnosis”, one expert explained, “children like these never received any kind of diagnoses in the past”. This meant there were a vast number of children waiting for a diagnosis. Extrapolating from prevalence studies conducted in the United States, some advocacy groups contend that real number is much higher, close to 450,000 individuals².

The assumption underlying the underdiagnosis theory was that diagnosis would bring families together in search of services geared towards children on the autism spectrum. It should be noted that the dominant form of special education for students with special needs in Turkey was in the form of segregated residential and day schools up until the early 1990s. While these schools were few in number with very long waitlists, they could only offer instructions in life skills and could not provide the rigorous training that is now accepted as the norm for children on the spectrum. The assumption was therefore that parents faced with the difficult obligation of providing their children with intensive individualized instruction would make increasing demands on the state. In addition to the pressure exerted by the parents, the expectation of state intervention is based on the idea that “untreated”, these children would be a “future threat” for the nation understood as an economic and social burden as one therapist explained. As the state

² This calculation is based on the prevalence rates of Western countries. “The global prevalence of autism is 1 in 150... While there are no reliable statistics in our country, (we can state that) based on the 1/150 rate, there are 450,000 individuals with autism and 125,000 children with autism between the ages 0-14 in Turkey. (Sütlaş August 23, 2008)

began to cover the expenses of this intensive one on one therapy, often up to forty hours a week, there would emerge a new market addressing the special needs of children on the autism spectrum. Into these market would flow professionals from various fields including early education, special education, psychology, physical therapy and occupational therapy. This theory should also be contextualized as a byproduct of the neoliberal understandings prevalent in Turkey during this period. This was a time when the state had begun to outsource many of the activities particularly in the fields of health and education to private entities. So the expectation was such that the state would intervene to create the conditions for a market to serve the needs of these families.

However, in this dissertation I will show that the Turkish case does not fit this typical diffusion model. Instead of an “autism epidemic” triggering new forms of organizations, interventions and meanings, the Turkish case exhibits a top-down introduction of autism in the areas of awareness, detection and intervention. As I argue below, unlike its Western counterparts, the “explosion” of autism in Turkey was characterized by the peripheralization of parental expertise and experience. While the involvement of non-governmental entities was considerable, I show that this type of organization differs greatly from the typical parent and patient organizations that characterize health movements around the world. Founded by “prominent figures” as they refer to themselves, these associations mainly serve as service providers particularly of special education. The founders of these organizations explicitly distance themselves from the parents and parents’ organizations. Their capital is not based on experience but on expertise gained in other fields such as business and philanthropy. They have worked as professionals in other fields ranging from tourism to construction and their interest in

autism could best be described as a philanthropic one. I argue that this picture is indicative of the configurations of expertise in contemporary Turkey. The exclusion of patients and families, while reflective of the organization of state-civil society relations in Turkey is also an important indication of the way in which autism is translated to the local context. Despite all these efforts in raising awareness, improving educational opportunities for children on the spectrum and educating the health care professionals, the number of children diagnosed with autism spectrum disorders remains strikingly low. The diffusion model remains insufficient to explain this puzzle since despite systematic and concerted efforts to bring autism to the public agenda, the total number of diagnoses has not shown any significant increase. In order to explain this puzzle, I argue that autism should be understood as a “disorder without a diagnosis” in Turkey as the interests of parents, experts and non-governmental organizations are aligned by a non-diagnosis. There is considerable effort by these parties to intervene early and intensively as if there is a diagnosis but they avoid the label of autism. As I followed the children through the processes by which they were screened, evaluated and treated, it became clear that the introduction and circulation of autism in the local context was based on an evasion of the diagnosis³.

Middle class parents steered clear from the label because it was stigmatizing, while the families of lower socio-economic backgrounds did not push for a diagnosis since their eligibility for services would not be any different if their children received a diagnosis of autism spectrum disorder or mental retardation. Parents don't tell stories of

³ Here I do not only refer to official diagnoses, which could only be given by psychiatrists and pediatric neurologists. I also refer to meetings with therapists, evaluations by psychologists, the attitudes of pediatricians as well as the parents.

catharsis of when they finally obtained the diagnosis, which is typical of the families' experiences in the West. Instead, parents find themselves drawn into an orbit of disability practices that range from "managed confinement" to normalization. More importantly, as the child showing symptoms of developmental delay enters this orbit, they face a polarized system. While middle class parents hope for eventual integration in a normal classroom and the eventual disappearance or shrinking of symptoms, lower class parents hope for the management of behavioral symptoms and finding normality in isolation. From a macro perspective, the lack of a diagnosis means less cooperation and support among parents and less bargaining power against the system of expertise represented by the network of psychiatrists, psychologists and special education experts.

The experts, on the other hand, did not have an interest in fixing a diagnosis and could cast a wider net of surveillance and intervention without resorting to any labels. This was particularly true since the field was characterized by the strong hold of the psychiatric profession, which laid claim to all practices of naming, labeling, screening and treating. Instead of challenging this authority, the experts composed of a variety of professional and para-professional groups such as special education teachers, occupational therapists and psychologists collaborated to form an alternative market to serve the needs of children exhibiting all kinds of delays, deviations, departures from the norm.

This dissertation is built on the observation that autism is an apt site to examine the standardization of normality and abnormality, the transformation of the relations of expertise as well as the emergence of anxieties over childhood. I use the case of autism to inquire how new forms of citizenship and personhood are being negotiated in a context

that is undergoing some crucial modifications in disability regulation, the provision of special education and civil society organization. One crucial outcome of these changes is that non-governmental organizations including foundations and associations have begun to take on the pursuit of raising public awareness as well as training a group of experts particularly professionals and undertaking the detection and treatment of children. While some of these organizations are founded by parents, the most successful ones are run by professionals. The puzzling consequence of the expansion of the diagnostic category of autism in Turkey is the exclusion of parents from these processes.

This contrast is all the more visible when we evaluate other cases where the participation of the patients and their families has been key to the epistemic journey of diseases. For example, in his study of AIDS treatment, Epstein has discussed the significance of patients in shaping the knowledge about the disease through what he calls “lay expertise” (1995; 1998). According to Epstein, the activists have been influential in the formation of “knowledge from below”. “They have challenged the formal procedures by which clinical drug trials are designed, conducted, and interpreted; confronted the vested interests of the pharmaceutical companies and the research establishment; demanded rapid access to scientific data; insisted on their right to assign priorities in AIDS research; and even organized research on their own, with the cooperation of allied professionals. Starting out on the margins of the system, treatment activists have pushed their way inside, taking their seats at the table of power” (Epstein 1998: 32). However, Epstein’s story does not do justice to the full extent of parent and patient involvement in contemporary health activism. What has taken place is not simply a distribution of power and authority but a re-construction of the field of expertise. One such example is

provided by Rabeharisoa and Callon in their study of the French Muscular Dystrophy Association (2004). They argue that what is taking place is a coproduction of scientific knowledge as a result of intense collaboration. Hence, patients and families are not simply becoming “lay experts” so they can engage with the specialists, but they claim authority to another form of knowledge as “experts of experience” (Rabeharisoa 2008: 25). This is particularly significant in the world of autism. As a disease with unknown etiology, variable manifestations and controversial therapies, autism is characterized by this collaborative knowledge production. As Eyal et al. argue, with autism, a new type of actor emerges, the “parent-activist-therapist-researcher” who “constitutes a new modality of expertise anchored in networks of knowledge exchange among parents, researchers, and therapists” (2010: 172).

Through a comparative lens, the uniqueness of the Turkish case is unmistakable. The translation of autism took place in relation to a particular social fabric characterized by distinctive understandings of institutions and normalization. While strategically placed mediators such as Western educated psychiatrists were involved in transposing the meanings of autism to the Turkish landscape, the diagnostic transferability of autism could not be sustained within the local institutional apparatus.

THE GLOBALIZATION OF AUTISM

Here is how the Autism Society of America defines autism: “ASD (Autism Spectrum Disorder) affects individuals in every country and region of the world and

knows no racial, ethnic or economic boundaries” (Autism Society of America 2006). This definition initially developed by the U.S. National Society for Autistic Children⁴ in 1977 and later approved by the American Psychiatric Association emphasized the universal nature of the course, symptomology and outcome of autism (Kuo-Tai 1987; Sanua 1984). However, this statement was challenged as early as the 1980s by some investigators who underlined differences observed in the prevalence of autism worldwide. In fact, based on a review of literature Sanua argued that “autism is an illness of modern civilization, and is therefore to be found primarily in countries of high technology, where there is extensive geographical and economic mobility coupled with the dominance of the nuclear family” (1984: 163). This dilemma has been central to the debates on autism: how do you reconcile the organic and biological roots of autism with the fact that it is found in such various frequencies in different parts of the world?

This quandary is reflective of the broader questions over the diffusion of mental health categories. Which metaphor best describes the spread of mental disorders globally? Is it a process of diffusion with an outward movement from the center to periphery, from the West to the East? Or does it entail the hybridization of theories, categories, practices and institutions, which implies dialogue and exchange within a larger transnational network? While there is a growing literature addressing the global transmission of culture and institutions, there is relatively less emphasis on the circulation of the classification, identification and treatment of mental disorders. One dominant strand has been the analysis of culturally specific ways of understanding and experiencing mental illness developed by what Arthur Kleinman has called “the New

⁴ This was the original name of the Autism Society of America.

Cross-cultural Psychiatry” school (1977). The most important theoretical contribution of this approach has been the critique of universalism espoused by the existing generalist models. Instead, Kleinman and his colleagues set out to analyze how somatic symptoms and practices of healing reflect the social, political and moral contexts from which they arise (Kirmayer 2006: 127). In addition to highlighting the cultural variation observed in the experience of diseases in the non-Western world, the new Cross-cultural Psychiatry school has argued for contextualizing Western medicine through studies which display that the Western biomedical theory and practice is a product of a specific cultural history. This meant a challenge to the widely accepted dichotomy of “universal” biology and “local” culture (Kirmayer 2007).

The increasing biomedicalization of psychiatric knowledge and practice has also been criticized from within the field by the critical psychiatry approach. The adherents of this school have warned against “McDonaldization of children’s mental health” as a result of changing conceptions of childhood and pharmaceutical interventions (Timimi 2010). Others have challenged the biomedical hegemony within psychiatry by emphasizing the role of communities in healing mental disorders (Thomas et al. 2009). Some studies which analyze the variation across cultures have stressed the different experience of mental disorders in other locales, particularly highlighting better prognosis as a result of various local and cultural resources available to them (Luhmann 2007; Myers 2010).

These debates were brought to public attention through the recent work of Ethan Watters who builds on these contributions and suggests that the diversity in the experience and treatment of mental illness is disappearing as a result of being “bulldozed

by disease categories and treatments made in the USA” (2010: 3). He argues that this loss of diversity is crucial as it suggests the loss of multiple modes of healing. Through the study of four case-studies worldwide (anorexia in Hong Kong, post-traumatic stress disorder in Sri Lanka, schizophrenia in Zanzibar and depression in Japan), Watters makes a case for the homogenization of the experience and treatment of mental health. He argues that the new Western ways of thinking about madness “are proving as seductive to the rest of the world as fast food and rap music, and we are spreading them with speed and vigor” (Watters 2010: 4).

What exactly are the processes through which the pathologies of the mind spread around the world? Is exporting McDonald’s to India the same thing as recognizing and treating depression in Greece? What is the nature of this flow? There is a wide literature addressing the spread of ideas, innovations, language, and social movements. The earlier explanations have focused on the role of imitation and imposition in transnational flows. Writing against the predominantly economic approach of Wallerstein’s world systems theory, Meyer and his colleagues argued that globalization also entails the diffusion of culture understood as the spread of norms, knowledge and practices (Meyer 1980). According to this perspective, transnational diffusion involves movement from a source (the innovator) to the adopters. In other words, “(c)arried by rationalized others whose scientific and professional authority often exceeds their power and resources, world culture celebrates, expands, and standardizes strong but culturally somewhat tames national actors” (Meyer et al. 1997: 173). The global predominance of a “rationalized world culture” forms the basis of institutional isomorphism or the global convergence of institutional forms (Boli and Thomas 1997). In this paradigm, the driving force behind

the adoption of global models in local contexts could be a number of different forces including maximization of legitimacy and reduction of uncertainty (Meyer and Rowan 1977; Powell and DiMaggio 1991).

The globalization of the American psyche as studied by Watters is embedded in the diffusion paradigm. According to Watters and others who defend the homogenization paradigm, the universal adoption of a transnational diagnostic code for mental disorders that is based on the biomedical explanation of diseases has been a crucial factor in the loss of indigenous ways of experiencing and treating pathologies of the mind. The global acceptance of diagnostic manuals such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) and International Classification of Diseases (ICD) implies the convergence of institutions based on epistemic and institutional isomorphism or the shared norms, expectations, and culture of the experts who occupy the field. The problem with the diffusion approach is its lack of attention to the actual processes and practices of circulation and the implications of a hierarchical relationship of transfer from core to periphery. These shortcomings are replicated in studies that are critical of globalization. While arguing against a conceptualization of globalization as simply Americanization, these studies replicate the isomorphism theory implicit in examinations of transnational dissemination. It does not involve a new conceptualization of globalization but rather shifts the focus to practices of resistance as they are observed in the periphery (Bockman and Eyal 2002). In this conceptualization, the boundaries between the diffusers and the receivers remain strong.

Instead of approaching the global spread of disease categories as a process of imitation and imposition facilitated by the adoption of universal disease classifications

and the hegemony of biomedical psychiatry, I argue that the disease category itself should be conceptualized as part of a larger network of relations (Latour 1987). The “liquidity” of a diagnostic category, that is its ability to appear in the same way in multiple places is “contingent upon its network of production and stabilization” (Lakoff 2005: 32). The recognition of a disorder requires certain institutional conditions to be met. For example, Lakoff’s study of bipolar disorder in Argentina demonstrates how the combination of several factors unique to this setting resulted in very few diagnoses of the disorder. Of particular importance were the dominance of the psychoanalytic paradigm and the suspicion towards biomedical understandings of disease (p.39). As Lakoff puts it, “(t)he absence of bipolar disorder in the mental health world of Argentina ...was not a matter of an incomplete ‘diffusion’ of knowledge from center to periphery, but rather of an unfriendly ecology of expertise” (p.5). Similarly, the diagnostic liquidity of autism is contingent upon the stabilization of the network, which produces, reproduces and black-boxes autism as a fact as Eyal et al. argue in the Autism Matrix. The findings on transnational comparison of autism prevalence are especially striking. The data shows how the high rates of autism require two institutional prerequisites: a large-scale deinstitutionalization in the field of mental health combined with the existence of a network of expertise consisting of parents, therapists and researchers.

Building on these studies that provide a new conceptualization of the global spread of mental illness, I provide a detailed analysis of how the adaptation and translation of autism to local conditions in Turkey cannot be understood within an Americanization paradigm. Instead, they should be examined as being contingent upon a completely different history of state-society relations, of the psychiatric profession and

the lack of deinstitutionalization. In order to analyze the movement of a diagnostic category, one should be particularly attentive to how it moves as a result of the enlargement of a network that includes instruments, theories, standards, institutions as well as actors. This requires a closer scrutiny of the mechanisms of local implementation. The local translators need to enlarge and strengthen the network to mobilize new resources. As Lakoff and Eyal et al. show, the “success” of a diagnostic category in a local setting is based on the capacity of actors to align their interests with the local recruits and the final black-boxing of the category.

I argue that the construction of the autism network in the Turkish case exhibited unique dynamics characterized by a history where institutionalization was almost non-existent, families were the primary caregivers, the psychiatric profession’s authority was not questioned and the advocacy efforts of the parents were relatively weak. The combination of these factors resulted in what I call a “disorder without a diagnosis”. Instead of focusing on diffusion as a unilinear process, I highlight the interactive and contentious dynamics of the process. In the case of autism, what was being translated was not simply a diagnostic category but the whole network that had enabled autism to be black boxed in the first place. That this network failed to reproduce itself in the Turkish context should come as no surprise given the unique local conditions of mental health care as described above. What is more significant, however, is that this failure could not simply be explained away as a failure of framing on the part of domestic translators or as the misfit between pre-existing ideas and imported concepts. Instead, this study focuses on the global insofar as it exists in relation to the local. The global agents who were strategically placed to translate autism to the Turkish context wielded their power from

their global networks which in turn was based on their ability to present autism as a replicable phenomena in non-Western contexts. However, they were unable to transpose autism to Turkey because it lacked a wide network of surveillance, special education, psychiatric care and parental advocacy upon which it could be grafted.

A NOTE ON METHODS

This dissertation draws from fieldwork conducted in Boston, New York and Istanbul between September 2007 and September 2009. While most of the dissertation draws from data collected through observation and interviews in Istanbul for over six months from April 2009 to September 2009 in Istanbul, I also employ examples from the United States as comparative cases. Even though this is not a thoroughly comparative study, the origins and the development of the autism epidemic in the West provides an important entry to the study of the diffusion of the disorder and its transposition to the Turkish context.

Most of the observations and interviews were conducted during this period. However, I also conducted some follow-up interviews by phone in 2010 and 2011. In Turkey, I conducted interviews with fifteen experts working in the field of autism including psychiatrists, psychologists and special education experts. I also interviewed ten parents whose children were either diagnosed with autism or were receiving special education services for developmental delays. In Boston and New York, I interviewed twenty-one parents and conducted observations at four different therapy centers.

I have conducted observations and interviews at the child psychiatry clinics of three major public university hospitals in Istanbul. My sample is not representative of the autism field in Turkey. One major limitation is that the collection of data took place only in Istanbul. I would expect to find very different dynamics in rural areas, particularly those where there is no child psychiatry department. The three university clinics were chosen because they were the only ones with child psychiatry departments. While families no doubt took their children to be seen at adult psychiatry clinics of other hospitals, but they had to be evaluated by a child psychiatrist in order to be eligible for state benefits so most of the children were eventually referred to these centers. It is safe to say most of the diagnostic work took place at these three clinics.

At the child psychiatry clinic of University A⁵, I have observed sessions two days a week for six weeks. I was able to stay in the room along with an assistant as the psychiatrist conducted his sessions. I was also present in the room both before and after the sessions while the psychiatrist explained the case to us. The psychiatrist that I observed was one of the most prominent child and adolescent psychiatrists in Turkey. He saw patients at the hospital only two days a week and the rest of the week he met with patients at his private practice. Most of his patients were adolescents presenting issues with what he saw “discipline at school and at home”. He was trained in France and is one of the founders of the Istanbul Psychoanalytic Society.

At the Medical School of University B, I observed sessions of a pediatric neurologist who specialized in pervasive developmental disorders and was a prominent

⁵ For purposes of confidentiality, I use pseudonyms instead of the real names of the institutions and participants.

advocate of the rights of children with autism. I observed the neurologist as he met with families and children once a week for eight weeks. He usually met with thirty to forty families on a given day. Even though most of these sessions were follow-up sessions, I was also able to observe some diagnostic sessions. Most of the patients who came in were children between the ages of eighteen months to fourteen years. Almost all of them presented with a range of developmental delays.

At the hospital of University C, I have observed sessions at the Department of Child Psychiatry two days per week for six weeks. These sessions lasted for more than an hour and most of the patients traveled to Istanbul to be seen by the child psychiatrist. I also attended the weekly rounds as residents presented their research. The psychiatrist that I observed is a very well known figure in the field. He was trained in the United States and he is a strong advocate of the standardization of mental health services.

I have also observed therapy sessions at a private clinic for six weeks in order to diversify my sample. This clinic was situated at an upscale neighborhood in Istanbul. This site provided a comparative perspective on how psychiatrists work with different populations, what type of psychological know-how they use and what kinds of classifications they adhere to. The patient profile was considerably different from what I observed in other settings although they presented with similar problems. I was also able to attend training sessions with young therapists, which focused on how to administer various neuro-psychiatric tests.

I have also conducted interviews and observations at an autism foundation and its school for children on the spectrum two days a week for eight weeks. This was a school, which offered intensive behavioral therapy for children with developmental delays. I

observed children during classroom activities as well as during non-structured activity periods. I also participated in meetings, conducted interviews with the teachers and the parents and observed private lessons.

I recruited the parents from the hospitals and the autism school. In this case, verbal consent was preferable since subjects are often unwilling to sign consent forms because of fear, mistrust or suspicion. In addition, signed consent forms are viewed with suspicion because they may identify subjects in sensitive research areas. In order to mitigate these problems, I approached the subjects through experts already established in the field. These experts, a child psychiatrist and the director of a school for children with autism spectrum disorders explained the study to the parents and made the introductions. Upon initial contact, I presented a brief description of my research and then arranged a meeting for a later date. When I met with the parents for the interviews, I presented them with a letter describing the study written in Turkish (for the English translation see Appendix One). After going over the information sheet with the parents, I asked for verbal consent given the sensitive nature of signed consent in Turkey. For those children who were able to give assent, I asked for their verbal assent. The parents that I met were unwilling to sign documents for the fear of exposure. Because of the high level of cultural stigma attached to mental disability in Turkey, parents often opt for hiding the disabilities of their children. Some parents had concerns about the confidentiality of the data that will be collected despite the verbal consent. I explained in detail the precautions taken to ensure the confidentiality of the subjects. Another problem that I faced had to do with my position as a researcher affiliated with an American University. Coming from a Western institution and dealing with such a sensitive issue as autism, parents were inclined to

view me as having some answers with regards to autism therapies or medication. Some parents asked me to evaluate their children, others wanted to know about the latest therapy techniques and yet others had questions about the causes of autism.

Some of the experts, on the other hand, were uncomfortable with talking to a researcher affiliated with an American university. This could partly be explained by a widespread anti-American sentiment among some therapists, particularly those working within the psychoanalytic and cognitive behavioral paradigms.

ORGANIZATION OF THE CHAPTERS

The first chapter begins with a historical analysis of the institutionalization of psychiatry in Turkey, situating it within the new nation's modernization project and its struggle to formulate a new kind of Western, modern citizenry. This is relevant in understanding the unique structural conditions in Turkey, particularly the division of clientele between psychiatrists and psychologists, the compliance of families in the provision of mental health care services and the relatively unchallenged authority of the psychiatric profession. This analysis provides an important background to understand the particular adoption and translation of autism in the twenty-first century.

In this chapter, I use both primary and secondary literature on the formation of the psychiatric field in Turkey. I provide an analysis of the emergence of a scientific field in a newly established nation by looking at how psychiatric expertise began to take root in Turkey beginning in 1920s. Throughout this period, medicine was viewed as a major instrument of modernization and social progress. The first section analyzes the formation

of a new professional class during the late Ottoman period with a focus on “belief in science” as an organizing principle among the newly established elite. Then I move on to analyze the institutionalization of psychiatry in Turkey through the twentieth century. I show how the organization of psychiatric care was based on the compliance of the families as the main caregivers of the mentally ill given the relatively few psychiatric beds available during this period. The psychiatric profession secured its legitimacy through resorting to biomedical explanations and treatments given lack of resources to provide long-term care for those with mental disabilities. This is a crucial differentiating factor in understanding how autism was introduced and translated to Turkey. The infrastructure that gave rise to the institutional matrix, which was influential in the identification, detection and treatment of cases, did not develop in Turkey. Instead, there was a network of regional hospitals that catered to local, mostly urban patients in outpatient clinics. The absence of this institutional structure meant a weak interest in the surveillance of pathology particularly as it exhibits itself in child development. The issue of child development abandoned by mainstream psychiatry and medicine later became the *raison d’être* of the psychological profession, which aligned itself with pedagogy. This division of labor had important ramifications for the conceptualization of autism in later years.

This chapter also provides an analysis of the role of psychoanalytic theory and method in the formation of Turkish psychiatry. I show that the predominance of the Kraepelin School in the formation of Turkish psychiatry has resulted in the organization of psychiatric knowledge through a biomedical perspective. Unable to enter the medical circles, psychoanalysis could only penetrate social imaginary through the literary field.

This trajectory is used to examine why psychoanalysis was not domesticated in Turkey until very recently. The failure of psychoanalysis meant a major delay in the expansion of individual therapy as well as the psychodynamic framework at the medical schools. This also meant that the penetration of psychiatry into the middle class family remained very restricted.

In the following chapters, I draw on the data collected during fieldwork and interviews to analyze the cultural aspects of the mechanisms of referral, diagnosis and treatment in autism. The analysis of the data reveals that autism in Turkey can best be understood as a disorder without a diagnosis. This is not simply because autism goes undiagnosed or misdiagnosed due to the underdeveloped nature of mental health services as would be the case in many other settings. I argue that there is a more complicated dynamic at work in the Turkish context. More specifically, I identify two divergent trajectories for children who might be showing impairments in communication or social interaction. Pure autism, the extreme cases of autism with behavioral problems and mental retardation are relegated to the institution, the public university hospital, while middle class parents form alliances with therapists and experts working in private clinics and try to prevent getting attached to the diagnosis altogether. I argue that in contrast to the American case, the parents and experts try to disassemble the autism spectrum so that the two moral careers do not converge.

In the second chapter, I analyze how the hospital as an institution has given rise to the diagnosis of “severe autism”. I focus on the particular technologies and practices that have enabled the construction and reproduction of this category. I argue that this institution could only give rise to such a limited definition of autism characterized by

extreme behavioral problems and that this classification has been successful because the psychiatrists were able to align the interests of the parents who visited the hospital not in search of a cure but in need of strategies for containment. Instead of categorizing autism as a developmental disability, which implies flexibility, a hope that the children could somehow “catch up” with intensive education and therapy, the hospital turned it into a fixed condition similar to mental retardation.

In the next chapter, I focus on the private clinic and the private autism schools, which work with a new moral image of autism emphasizing the critical window of opportunity and the possibility of normalization and integration. The idea of a critical period is crucial in the differentiation of autism from mental retardation. According to this theory, it is possible to “rewire” the neural pathways of the brain during the early years because of the plasticity of the brain. Through intensive intervention, children exhibiting developmental problems may be able to continue to general education by kindergarden. The critical window of opportunity implies an “economy of hope” and the possibility of improvement and change and this is how autism differs from mental retardation which implies a fixed state (Eyal et al. 2010; Rose and Novas 2004). The professionals who were able to build this new network based on this “economy of hope” consist of psychologists, teachers, special education experts and therapists. Working outside the mandate of the psychiatric profession, these experts ally with middle class parents in forming a space for individualized intervention. I argue in this chapter that the most significant factor that has enabled the experts to formulate an interpretation that enabled them to align their interests with that of the parents was working without adhering to a particular diagnosis. Without resorting to the classification of autism with

its connotations of severe behavioral problems and a fixed state, these experts were able to create a new space for the detection and treatment of autism.

In the last chapter, I turn to the role of civil society in the translation of autism to the Turkish context. The chapter begins with an analytical discussion of the historical relations between state and civil society paying particular attention to the changing role of the welfare state. I then provide an examination of the rise of the parent as activist-therapist in the West. In the last section, drawing on my fieldwork, I analyze the rise of a new type of civic understanding in the autism field and examine the resulting frictions within the parent advocacy community. I argue that this new form of organization has been successful in mobilizing resources because it could incorporate itself to the transformations of the welfare state. In this way, it has formulated a new form of advocacy that is not simply based on service provision, which was the dominant form of parental activism until then.

Chapter 1

The Institutionalization of Psychiatry in Turkey

When I began my fieldwork at the neurology department of a university hospital in Istanbul, I was eager to make local contacts, parents that I could meet later to gain a better insight into the processes of getting a diagnosis, getting referrals and getting access to various treatment strategies. The first family I met at the waiting room had come from a town at the Western border of Turkey, a five-hour bus ride to Istanbul. They told me they make the trip once or twice a year since there is “no one like *hodja* in their town, no one with his credentials”⁶. It turns out that most of the families waiting to see the neurologist that day had come from different parts of the country, some of them traveling for more than 20 hours on the bus just to meet the *hodja*.

This was in itself a significant indication of the way psychiatric care is organized in Turkey. As I argue in this chapter, the system is extremely centralized with psychiatric hospitals established strategically to serve the different regions. The absence of community mental health care centers often results in long commutes and the lack of follow up care. More significantly, the hospital-based system conceals the class bias that

⁶ People often refer to medical doctors as *hodja* meaning teacher, professor. The word *hodja* primarily carries the meaning of a spiritual teacher, which is reflected in the way the relationship between the doctor and the patient is organized. As the doctor receives his patients, he is treated with great reverence, the families taking great care not to interrupt him or even to turn their back to him.

is so characteristic of the way psychiatric care is distributed in Turkey. An analysis of this peculiar structure is essential in understanding the landscape of mental diseases in contemporary Turkey particularly the widespread conviction that mental illness is a disease of the poor. Even the former chief of staff of the Bakırköy Mental Health and Neurology Hospital, the largest psychiatric hospital in Turkey, considers most of the inpatient population to be “poor in general” (Yanık 2011). In this dissertation I will show how this equation has been influential in concealing the ways in which different classes, when faced with psychiatric impairments, often find themselves in divergent trajectories with radically different outcomes.

In order to understand the emergence of autism and childhood pathology in contemporary Turkey, this chapter provides a historical analysis of the detection, surveillance and treatment of mental illness and mental retardation. As Eyal et al. show, as a result of certain historical contingencies including deinstitutionalization and parental activism, autism has been placed somewhere between mental illness and mental retardation, though closer to the second one. However, in doing so, autism has fuzzified the boundary between the two, challenging the notions of treatment and cure since it implies a “hope for a cure”, a potential particularly within the idea of a critical window of opportunity (Eyal et al. 2010: 31-3). Even though the Turkish case shows marked differences compared to the American one, these trajectories are still essential to understand the structure of the field of intervention in autism today.

This chapter begins with a historical analysis of the institutionalization of psychiatry in Turkey through an exploration of its origins during the Ottoman period. The most significant aspects of the organization of the field have been the struggles between

the religious and the secular (Western) understandings of mental health as well the strife between the biomedical approach and alternative schools of thought. Through this historical narrative, I examine the origins of the organization of psychiatric care with particular emphasis on the predominance of confinement as the main strategy of healing and the lack of deinstitutionalization and the delay in the introduction of community mental health care. I then turn to the history of psychoanalysis as a failed project in the history of mental health care. Even though the introduction of psychoanalysis dates back to the late Ottoman period, it was not well into the 1990s that psychoanalysis began to gain visibility. The predominance of institution-based psychiatry had prevented the development of an individual based therapy.

The following section will provide an analysis of the history of mental retardation in Turkey. I will show how unlike mental illness, mental retardation has primarily been a jurisdiction of psychologists and educators. Beginning with early interest in mental hygiene in the 1930s, this focus on mental deficiencies has been crucial in the formation of particularly psychology. Through the development and application of intelligence tests as well as work on the classification and prevention of mental retardation, these professions tried to carve a space for themselves against the growing hegemony of organic psychiatry.

1.1. PSYCHIATRY AND THE WILL TO MODERNIZE

The origins of the organization of psychiatric knowledge and care date back to the modernization efforts of the late Ottoman period. While there were centers for healing

the mentally ill established during the early years of the empire, they were organized around humorous, Islamic and traditional forms of healing. The organization and provision of therapy was very different in the Ottoman period. For those with financial means, healing took place exclusively at home by physicians who paid house visits. The patient with means did not visit the physician, nor did he set foot at the hospital. In fact, the hospital was a place of care for “the poor, the miserable, the needy and the weak” (Shefer-Mossensohn 2009: 117). In addition, the medical care system was characterized by a pluralism which included physicians who were trained in traditional religious schools, those who were trained under a master/apprentice system, local healers as well as healers of the Islamic sufi orders, and the dervish orders.

The modernization and institutionalization of medicine meant claiming jurisdiction from these diverse providers of healing and centralizing the system of healthcare at the hospitals. This was particularly difficult in the case of psychiatry, which had to legitimate itself as a new form of expertise and create its own clientele. Psychiatry had to “give itself away”, “to lend its vocabularies, explanations, and types of judgment to other professional groups and to implement them within its clients” (Rose 1996b: 33).

As psychiatric expertise began to spread into the regulation of education, family, urban life, it consolidated its position. However, this was not an uncomplicated history. This consolidation took place as psychiatry became a part of the modernization and nationalization project of the newly founded Turkish Republic. Unlike the young Republic, the Ottoman state was not interested in the surveillance, detection, and treatment of madness since the idea of “governing a population” had not yet taken roots. It was not until the early 20th century that madness was transformed into a “social

danger” that could only be contained through confinement (Ayhan 2005). In the creation of modern, civilized citizenry, psychiatry became an important tool for the state elite. This period also marked the promotion of the psychiatric expert as the sole recognized authority to deal with the problems of the soul. However, as I argue below this is still an ongoing process since most of the patients suffering from mental health problems continue to frequent Islamic clerics in search of cures.

Pere Mongeri, who is often referred to as the Pinel of the Ottoman mental healing, was influential in the formation of the earliest Western style institution⁷. According to Ayhan, this period was characterized by an extreme polarization between the religious discourse and medical sciences, which were just beginning to spread in the Empire. She argues that the competition on the jurisdiction over the human being was resolved by an implicit division of labor whereby “the knowledge of the human body would be guided through scientific methods and rationality (i.e. medical sciences) and the knowledge of the human soul would be guided through religious faith and principles” (2005: 160-1). She further argues that this strife could only be overcome by the efforts of an outsider with access to the expert knowledge developed in the West. The significance of Mongeri was that he was influential in the institutionalization of psychiatry particularly through the regulations he introduced for admission and discharge from the asylum.

The real thrust for the institutionalization of the field arrived as psychiatry was incorporated into the project of modernization and nationalism with the formation of the

⁷ Philippe Pinel was an important figure in the history of psychiatry particularly in France. He believed that mental illness was treatable and this could be achieved through a new approach known as “moral treatment”. Instead of involuntary confinement and physical violence, Pinel advocated an early form of occupational therapy.

Turkish Republic. The history of psychiatry in Turkey is characterized by the ever growing power of organic and biological psychiatry. In the will to modernize, all alternative schools of thought have been marginalized. This has important consequences for the latter organization of the field.

The rise of a professional middle class was one of the most transformative aspects of state society relations during the late Ottoman period. These were intellectuals who had taken advantage of the new secular educational opportunities that had opened up as a result of the modernization reforms. The growth of a professional class was related to the establishment of western style schools as well as new programs through which students were sent to Europe for higher education. This coincided with the decreasing power of the *ulema*, the religious class, at least on an official level as more and more European physicians were recruited to oversee the well-being of the military (Özdalga 2005).

Educational reforms were influential in the formation of what could be called the “scientific habitus” of the Ottoman and later the Turkish elites. Most of the Republican leaders were graduates of the military academy (*mekteb-i harbiye*), military medical school (*mekteb-i tıbbiye-i askeriye*) and civil service academy (*mekteb-i mülkiye*). They shared similar backgrounds, similar education, and similar ambitions (Zürcher 2005). According to Hanioglu, one of the defining features of the new elite was their espousal of science as the panacea for the ills of the Ottoman Empire, particularly against its traditional and Islamic structures. Their world-view was based on an “epic struggle between religion and science, one that would inevitably end with the triumph of science and its coronation as the new and

definitive belief system” (Hanioglu 2011: 51). Within the medical field, this perspective meant an increasing emphasis on biomedical explanations and treatments and the exclusion of unreason and religion. According to Dole “in the realization of this new society and citizenry based upon reason, rationality and science, medicine assumed a vital position” (Dole 2004: 258).

The story of a shared authentic past that could be recovered from the ruins of the declining Ottoman Empire was essential in creating some kind of coherence and in controlling the contingencies and contentions within this heterogonous group. More importantly, this account of a “golden age” in which the Turks had discovered and applied the humane teachings of mental health while the West was “torturing” the mentally ill provides an important script to situate a newly forming elite network in relation to its European counterpart and against a wide network of religious healers ⁸.

In her study on madness in the Ottoman Empire and Turkey, Ayhan argues that study of psychiatry in the Turkish context “provides a useful window to Turkish ‘modernity’ as a whole” (Ayhan 2005: 34). She provides a detailed history of madness in the Ottoman and Turkish lands where she emphasizes the synchronicity of a new way of rationalizing and moralizing madness and the “gradual emergence of the modern state apparatuses and the underlying transformation of the social, economic and demographic dynamics in the society” (p. 36). This relation between

⁸ What is more interesting is the continuation of this trope into present day historiographies. Such an attitude could be explained by the precariousness of the psychiatric profession in a country where the first step in dealing with mental problems is still not psychiatric care.

psychiatry and the formation of the modern citizenry was crucial in the formation of the field. However, psychiatric expertise could not turn itself into the widespread projects of surveillance that is so typical of the histories of governmentality in the West. Instead, it remained mainly as an expertise confined to the boundaries of the mental hospitals and could not penetrate into the micropolitics of social life. In the following sections, I will discuss some of the reasons why institutionalization and confinement remained as the most important technologies of healing in the field of mental health. I will also include an analysis of the rise of organic psychiatry and the struggle to silence alternative approaches to detecting, diagnosing and treating mental illness.

1.1.1. THE INFLUENCE OF THE GERMAN SCHOOL IN TURKISH PSYCHIATRY

Turkish psychiatric tradition was heavily influenced by the German school, particularly by Emil Kraepelin who was a mentor to several of the pioneers of psychiatry in Turkey. Kraepelin was a late 19th century German psychiatrist famous for his work in the taxonomy of psychiatric disorders and disease categories (Berrios and Hauser 1988; Kahn 1957). In his classification of disorders, Kraepelin dismissed any search for underlying psychological causes or any insights into “motivation, dynamics and the deeper understanding of human behavior” (Weckowicz and Liebel-Weckowicz 1990). He was interested in providing a classification based on symptomology, course of development and prognosis. According to Young,

Kraepelin's approach could be summarized in three main points: mental disorders were to be understood in analogy with physical disorders, classification was to be based on observable symptoms, mental disorders have organic and biological causes which will be uncovered with time (Young 1995: 96).

The three generations of psychiatrists who were influential in the institutionalization of psychiatry in Turkey had all either worked with Kraepelin or were influenced by his ideas. The first generation is represented by Reşit Tahsin (1870-1936) who finished his education in psychiatry in Germany and began practicing psychiatry during the Ottoman period. He published his *Seririyat-ı Akliye Dersleri* in 1920. This was essentially a collection of his lectures at the Military Faculty of Medicine in which he offered detailed classifications of mental diseases in the Kraepelian manner and also included presentation of cases that would benefit the students of mental health (Şehiraltı 2001). Later Mazhar Osman (1884-1951) and Fahrettin Kerim (1900-1987) who had both worked under Kraepelin were influential in introducing the Krapelin School to Turkey in the years following the foundation of the Republic (Narter 2006; Oğuz 1996; Öncel and Erdemir 2009-2010). The three generations of psychiatrists have been influenced by his organic and descriptive approach and his anti-psychological stance. According to two contemporary psychiatrists, the importance of Kraepelin for Turkish psychiatry can't be understated:

If one were to inspect the history of psychiatry in Turkey, he would encounter Kraepelin's name the most. ... These professors (Reşit Tahsin and Mazhar Osman) utilized Kraepelin's

classifications ceaselessly and the young psychiatry specialists are doing the same now...The educational foundations of all Turkish psychiatrists are based on Kraepelin's works (Erkoç and Kutlar 2003).

In fact, the influence of Kraepelin was long recognized as can be observed from the article published in 1926 in an issue honoring his 70th birthday⁹. This article prepared by the prominent psychiatrists of the time, İhsan Şükrü and Fahrettin Kerim, recognizes the importance of his school of thought for the institutionalization of psychiatry in Turkey. What made Kraepelin so appealing to Turkish psychiatry was its insistence on discovering and categorizing the organic essence of diseases¹⁰ (Erkoç and Kutlar 2003). The introduction of psychiatry through this school had important ramifications for the later development of the field. Initially, this meant extensive efforts at classifying mental diseases. Almost all of the earlier works published in the field of psychiatry were aimed at demarcating nosological categories. Kraepelin's anti-psychological approach was crucial in the later formation of Turkish psychiatry (Yazgan 1991). The interest in biological and organic causes of disease pushed the field further into the hospitals while alienating other professions who could lay claim to the jurisdiction of diagnosing and treating mental illness particularly psychologists and social workers or pedagogues.

⁹ Some sources mention the visit of Kraepelin to Istanbul during the oppressive reign of Abdulhamid II (1876-1909). During this period, the only mental hospital in Istanbul at the time, Toptaş Bimarhanesi, had closed its doors to the outsiders and even Kraepelin could not gain access. (Kayaalp 2004; Yalçiner and Hanoğlu 2001)

¹⁰ The predominance of Kraepelin in Turkish psychiatry was criticized by İzzeddin Şadan who represented the psychoanalytic school.

1.1.2. MAZHAR OSMAN AND THE FORMATION OF TURKISH PSYCHIATRY

Possibly the most well-known figure in the history of Turkish psychiatry is Mazhar Osman so much so that his name has been synonymous with madness. Not only was Mazhar Osman important in introducing modern forms of treating the mentally ill but he was also responsible for expansion of the symptomological field and the somatization of mental health. A charismatic speaker and prolific writer, Mazhar Osman was a very important figure in the legitimacy struggles of Turkish psychiatry. He organized public meetings on mental health and published a psychiatric journal with his students, *Istanbul Seririyatı* (Istanbul Clinics) which not only included medical articles but commentaries on daily life (Şahinbaş 2010).

He was also known for his public demonstrations where he hypnotized the patients or used strychnine on paralyzed patients and “performed miracles”. In fact he was referred to as the “Turkish Messiah” (Güvenç-Salgırlı 2009: 97). Similarly, Reşit Tahsin, the founder of Turkish psychiatry, was known to perform “prophet-like miracles in front of the electricity box everyone was scared of by treating facial and hysterical paralyses” (Ayhan 2005: 214). By utilizing the vocabulary of the divine order, these miracles were important performances in the widening legitimacy of the field of psychiatry.

By purifying disease categories from polluting factors including superstitious beliefs, religious cures but also from psychology and psychodynamic therapy, the experts could solidify their position in the field. This was also an essential part of the

boundary work that was taking place at the time particularly that of affiliating psychiatry with medicine and not with metaphysics or humanities. According to Uzman, psychiatry was to be a “promising branch of medicine which is founded upon knowledge, experience, laboratory, clinical and microscopic research” (qtd. in Ayhan 2205: 229).

Latour’s conceptualization of modernity as simultaneous processes of purification and hybridization provides a fertile ground to analyze the transformations that occurred in early 20th century Turkey. Latour is critical of traditional accounts that equate modernity with progress, science, development and secularism as can often be observed in official historical narratives detailing the foundation of the Turkish Republic. As actors engage in boundary work, they are simultaneously involved in hybridization and purification mechanisms. According to Latour, this is the essence of knowledge production. While the network grows as new resources are mobilized, this is made possible as a result of the hybridization of practices, configuration of new regimes of knowledge through translation. On the other hand, their continued reproduction is guaranteed through the means of purification whereby the formation of hybrids is concealed.

In the Turkish case, legitimacy of medical expertise lay in successfully purifying the biological essence of diseases, particularly mental diseases. However, the result was often the manufacture of mixtures that combine different kinds of therapeutic and nosological systems. In her study on eugenics in 1930s Turkey, Güvenç Salgırlı discusses the attitude of the newly professionalizing medical experts’ attitudes towards the public’s recourse to local healers. She argues that such action is interpreted as “having supernatural beliefs” and “uneducated manners” or being “uncivilized,

primitive” (Güvenç-Salgırlı 2009: 54). She gives the example of the *Almanac of Health* with entries from three hundred doctors published for the tenth anniversary of the foundation of the Republic. According to Güvenç-Salgırlı, this book of diseases was aimed at introducing “the rules of hygiene” and instructing the public to see a doctor when faced with an illness. Those who didn’t abide by these rules were again condemned as being ignorant (p. 55). However, as the author notes, the text itself is reflective of the negotiations that were taking place between the new medical experts and traditional healers. For example, homeopathic cures and traditional forms of healing are also included in the book so as to appeal to the public at large. In this competition against the religious healers, Turkish psychiatry utilized the symbolic world of traditional healers and borrowed the trope of the “doctor as magician” while at the same time marginalizing traditional knowledge and practices as pure superstition and insisting on the biomedical essence of medical knowledge.

This expansion of medical expertise could be interpreted as a kind of boundary work in terms of trying to bring various concerns under the purview of medicine. Ultimately, the psychiatric experts were trying to carve up a space for the legitimation of psychiatry, to prove that it is a real disease. Especially in the early years of the Republic, psychiatry had to bring the mad back from the marginal spaces to which they were banished (Ayhan 2005: 93). Most of the sources addressing the role of psychiatry in the early years of the Republic reduce it to a mere instrument of the modernizing elites¹¹. Indeed it is not difficult to interpret the observations above and interpret these historical developments so that the institutionalization of psychiatry appears as an extension of the

¹¹ See for example Batur and Aslıtürk 2006

increasing penetration of state apparatuses.

However, as could be observed from the ambiguities the spread of psychiatry took the form of Eugenics and did not involve any meaningful attempt at sophisticated measures of mental health or surveillance at large. The fact that psychiatric work was organized around eugenic concepts and practices meant a clear disregard for the patient. This was in line with the elitism of the Republican cadre and the tendency to dismiss the experience of the patient and the family as secondary to the somatic essence of the disease became a permanent feature of Turkish psychiatry.

1.1.3. DE-POLITICIZATION OF PSYCHIATRY AND THE RETREAT TO THE ASYLUM

The influence of Mazhar Osman remained strong in Turkish psychiatry until the 1950s. During this period, Bakırköy Hospital was the main center for the treatment of the mentally ill. Even though two other psychiatric hospitals were established in the 1920s in other parts of the country, they did not exert much influence in the provision and organization of care (Sarı and Akgün 2008). Until the discovery of the antipsychotic agent chlorpromazine in 1955, the main form of treatment for schizophrenia, severe mental retardation, suicidal depression, manic excitation and persistent obsessive compulsive disorders was incarceration and the use of electroconvulsive therapy and insulin shock therapy¹² (Zahmacıoğlu, Dinç and Naderi 2009 : 313). It should be noted

¹² According to this method, the patient would be administered large doses of insulin to produce comas, which were believed to have a therapeutic effect. (Sarı and Akgün 2008)

that the largest mental health hospital, Istanbul Bakırköy Hospital, served more or less as a warehouse institutionalizing patients for up to 30-40 years. According to Koptagel İlal, patients who could not be accommodated in other hospitals in Istanbul (and elsewhere) would be transferred to Bakırköy where no patients were rejected (qtd. in Ayhan 2005: 251). In this period, psychosurgery, especially lobotomy was also used as a means to contain the inpatient population (Zahmacıoğlu, Dinç and Naderi 2009).

Institutionalization combined with the predominance of the medical paradigm, particularly the organic point of view resulted in an emphasis on psychopharmacology and neurology after the 1950s. The predominant form of treatment continued to be medication without the integration of rehabilitation programs (Yazıcı et al. 2007: 17). There were almost no attempts at rehabilitation or the introduction of a decentralized system of community mental health care until the 1970s. Bakırköy remained as the main provider of services as well as the center of training for those who wanted to specialize in mental health until the foundation of Ankara University Department of Psychiatry in 1945 and the Istanbul University Department of Psychiatry in 1955. Despite the adoption of the Law for the Socialization of Health Care in 1961, the first day hospital and community health care center were established in the early 1970s in Istanbul. However, these experimentations did not last long (Gökalp and Aküzüm 2007: 9).

Despite the predominance of the asylum structure in the field of mental health, the rate and scale of institutionalization never reached the levels observed in Western European states. There were not enough psychiatric beds or institutional facilities to accommodate a large number of patients. The available beds were mostly occupied by

adults suffering from psychosis or severe mental retardation. Given the limited availability of day hospitals and outpatient clinics, the majority of the care was assumed by the family, in most cases the extended family. In spite of attempts to reform the structure of the hospital, Bakırköy continued to function as a warehouse even in the mid-1990s. According to a resident, “it was worse than anything you could imagine, the reality was that if Foucault could see this place he would be talking about Nazi concentration camps, not prisons” (Çığışar Ziegler 2009: 148).

In spite of sporadic attempts at introducing dynamic psychiatry at the clinics of university hospitals, the picture remained more or less static until the coup d’etat of 1980. At this time, there were only four mental hospitals in Turkey with insufficient number of psychiatric beds often leading to overcrowding. The limitation of mental health work to the boundaries of the hospital was no coincidence. The tumultuous political past of the Turkish Republic confined the influence of psychiatry to the large hospitals. One psychiatrist explains this lack of interest towards the community at large.

Psychiatry in Turkey could not absorb any dialogue that would indicate a possibility of existence outside the medical paradigm. ... All mental health problems are still primarily dealt with at the hospital and to use an agonizing metaphor, unless we face the danger of the clinics literally tumbling down upon us, we won’t be able to remember the existence of a society outside the clinic. The best example is the August earthquake¹³. Those who were engaged in a nosological and

¹³ This was an earthquake of massive proportions often referred to as the 1999 Izmit Earthquake. It was crucial in the reorganization of the field of mental health in Turkey leading many urban based mental health workers to engage with populations they had not dealt with before.

even ideological debate on the existence of post-traumatic stress disorder became “fast traumatists” after the earthquake (Dindar 2005).

Dindar then goes on to explain the ideological reasons for the refusal to deal with trauma as a psychiatric category until the earthquake. He argues “(t)he reason is simple: before the earthquake trauma was synonymous with torture, trauma studies were synonymous with being a leftist” (p. 205).

There are examples of mental health workers organizing to resist the political oppression of the state in other parts of the world, particularly Latin America¹⁴. This was not the case in Turkey. Turkish psychiatry remained disconnected to the wider political and social concerns of the community. Keklik argues that a focus on social injustice has been discouraged since these issues were understood to be “delicate issues” which has pushed the field to concentrate on the internal psychological processes of individuals. This has also prevented the mental health care worker to advocate on behalf of her patients (Keklik 2010: 94).

1.1.4. THE DEVELOPMENT OF CHILD PSYCHIATRY

One of the main concerns during the early years of the Turkish Republic was public health. There was a growing interest in maternal and child mortality, ensuring the continuity of the population by increasing the fertility rate as well as the protection of children at risk, most of them orphaned as a result of long years of continued wars. The

¹⁴ See for example Hollander 2010.

state supported pronatalism, encouraged childbirth and took measures to train parents in modern childrearing practices (Gürsoy 2010: 142). With a desire to create a healthy nation, the Republican elite engaged in demographic reforms influenced by the eugenic tendencies of the period. In addition to adopting a pronatalist discourse, they also supported what has been called the “reform of the race”. According to Öztan, during this period there was a wide literature on how to raise “healthy children” and how to promote racial hygiene (Öztan 2011: 130).

The medical elite of the 1930s was influential in the promotion of a eugenic understanding of public health. While these ideas were widespread, their implementation was confined to the promotion of the nation’s health through disciplining the body and the family or what Alemdaroğlu calls “positive eugenics” (Alemdaroğlu 2005: 70). Through collaborations with psychologists, pedagogies and educators, they developed measures to detect and classify “degenerate children” including those with mental retardation. This was a crucial alliance that did not last long as I argue in the later pages of this chapter. As psychiatry moved away from eugenics, it also lost its interest in these larger “social problems”. The detection and surveillance of childhood was handed over to other professions.

While this interest in eugenics and racial hygiene was definitely not unique to the Turkish case¹⁵, the difference lies in the significance of this moment where there grew an alliance around the will to intervene in the social and political order. This short lived

¹⁵ There is an extensive literature on eugenics and the development of hereditary science in other parts of the world. See for example Adams 1995; Kevles 1986; Proctor 1988 (Kevles ; Proctor 1988)

alliance had important consequences for the organization of the field what can be called childhood problems. As it failed to develop any meaningful intervention strategies particularly for the group it classified as “severe mental retardation”, child psychiatry moved towards assuming a role in diagnosis and left the playing field to psychologists and educators.

The earliest organized effort to deal with mental health in children dates back to 1934 when a new ward for “idiot children” was opened at the Bakırköy Mental Hospital. This ward functioned like a warehouse where children with severe mental retardation and behavioral problems or children with neurological complications were institutionalized together (Çuhadaroglu 2010). However, psychiatric institutionalization of children was not widespread at least in mental hospitals¹⁶. Most of the work during the 1930s went into identifying the particular attributes of degeneracy. According to Güvenç-Salgırlı, the detailed scientific categorization was limited to the population of children and one could not find such extensive efforts with regards to the adult population (2009: 108). This preoccupation with diagnosis and classification continued into the 1940s and 1950s. The first Child Psychiatry Institute was founded by İhsan Şükrü Aksel at Istanbul University in 1956 (Polvan 2000). The purpose of the institute was:

¹⁶ Some of the children with mental retardation and other mental problems could be institutionalized in centers run by the Child Protection Agency as I discuss in more detail in the following pages. There were also a limited number of boarding schools run by private foundations. However, institutionalization of children with mental retardation was by no means the norm. Most probably those who were able to “pass” somehow attended mainstream schooling. The rest were cared for at home.

the detection of mental illnesses and mental and personality traits in children, the prevention of possible defects, conducting research on the distorted socialization of these children, foundation of clinics, production of publications, organization of conferences to train the society, cooperation with the parents of the diseased children when necessary, and increase relations with schools.

(Aydoğmuş 2009: 3)

The institute was an inter-disciplinary effort that included experts from the departments of psychiatry, neurology, pediatrics, forensic medicine and psychology. While it was suggested by one of the psychologist that it would be more appropriate to call this center the Institute of Child Development and Guidance, similar to its Western counterparts, his proposal was rejected. This proposal should come as no surprise as it was made by Walter R. Miles of Yale University who was a visiting professor at Istanbul University at the time who must have been very familiar with the child guidance clinics which were prevalent in the United States (Birand 1956). These clinics were established by the National Committee for Mental Hygiene between 1920s to 1940s for the “psychiatric study, treatment, and prevention of juvenile delinquency and conduct and personality disorders in 3-17 year old non-mentally retarded children” (Wright and Flanagan 2010). While the Child Guidance Clinics were established to manage the mental well being of middle class children, the Child Psychiatry Institute and the Guidance and Rehabilitation Centers were geared towards lower class children with mental retardation and behavioral problems.

In the 1960s, the first Child Psychiatry Departments were established, one at Istanbul University and the other at Ankara University. Both of these departments were founded by experts trained in the United States. This was also the period when

psychodynamic explanations were on the rise under the influence of the American paradigm. For example, of the six doctoral dissertations defended at the Department of Child Psychiatry Department of Istanbul University during the 1970s, three were on the relationship between the child and the parents¹⁷.

While child psychiatry as an academic discipline was recognized in the 1960s, the number of graduates who specialized in this field was never enough to exert any kind of substantial influence. The title of an article written by a prominent child psychiatrist is very telling in this regard: “Child Psychiatrists in Turkey: only 35 for ten million children and adolescents” (Yazgan 1997). According to the World Mental Health Atlas in 2005, there were about 200 experts working in the field, which meant 0.3 psychiatrists per 100,000 people (the same figure for the United States was 22 per 100,000) (2005). Currently, the Turkish Association of Child and Adolescent Psychiatry puts the number at 246¹⁸. While this number is negligible, the fact that they have “almost exclusively worked in medical schools and teaching hospitals” has also set severe limits to the spread of child psychiatry (Yazgan 1997: 14). Most of this therapeutic work has been outpatient therapy as the number of psychiatric beds remained well below Western standards. As of 2008, there were only 93 beds in various public hospitals for children and adolescents with mental illnesses and 56 for those with substance abuse problems (Güvenir and Varoltaş 2008).

The post-1980 period was a time when biological explanations and pharmaceutical solutions gained increasing importance. New departments were

¹⁷ For a full list of dissertations see <http://www.istanbul.edu.tr>

¹⁸ Önder, Okşan. 2012. Telephone Interview by author, Ankara. May 12

established and the number of child psychiatrists increased. The literature describes this period as an example of true globalization especially with the adoption of the Diagnostic and Statistical Manual of Mental Disorders (DSM) throughout the psychiatry departments (Oğuz 1996). However, as I will show in the following chapters this was a period when contestations within the community was on the rise particularly between those inclining towards dynamic psychiatry and others who believed in biological psychiatry. Especially after 1990, there was growing interest in autism spectrum disorders and attention deficit disorder. For example, out of the 33 dissertations defended at the Child Psychiatry Department of Istanbul University since 1990, eight are on autism and two are on attention deficit disorders. However, as I show in the following chapters this remained to be a theoretical interest at least in the case of autism. Child psychiatry was locked in a position of description and they were not interested in undertaking any large-scale attempts at intervention. In this sense, their interest was not that much different from the earlier studies on mental retardation.

1.2. WHATEVER HAPPENED TO PSYCHOANALYSIS: THE PATH NOT TAKEN

The introduction of psychoanalytic theory to Turkey dates back to the early 20th century. According to most sources, the first article on Freud was published in 1917 even though there is some indication that the psychiatrists of the time, particularly Mazhar Osman had limited familiarity with psychoanalytic theory even before this publication (Taştan 2011: 269). Despite this relatively early entrance, its reception has been extremely limited until the 1990s. Even so, it is a case that merits some further

discussion for two major reasons. First, this was definitely an important battleground for psychiatry as psychoanalytic theory presented a challenge to the newly established field. More importantly, the failure of psychoanalysis to thrive was intrinsically bound to the institution based treatment of mental illness in Turkey. In order for the dynamic view to be adopted, psychiatrists had to begin approaching the patients as subjects with an authority to participate in the process of therapy.

Conventionally, the institutionalization of psychiatry in Turkey is told in such a way as to preclude any discussion of struggles, disagreements and contentions. As I argued above, the presence of traditional healers is evaluated as superstition and dismissed as remnants of a disappearing Ottoman past. Similarly, the influences of Freud and psychodynamic theory are not included in these accounts. Kayaalp argues that compared to Japan and Latin American countries, the true penetration of psychoanalysis in Turkey was delayed by a century. According to Kayaalp, the Westernization efforts of the early 20th century had made the environment conducive to the development of psychoanalysis. However, it was the relentless resistance and even hostility of psychiatry even before the development of neurosciences that prevented the development of Freudian thinking (Kayaalp 2004: 121).

The influence of Mazhar Osman is so great on the subsequent generations that the publication of a recent biography, which included unfavorable details on his personal life, was enough to cause strong feelings in the psychiatric circles. The idealization of historic figures is very typical in the Turkish context as exemplified by the iconic status of Atatürk, the founder of the Republic, in the national imaginary. The influence of Mazhar Osman grew as a result of what is known as the University Reform of 1933.

This was essentially an attempt to restructure the university education in Turkey by incorporating scholars who had fled from Nazi Germany. Even though it was indicative of the increasing authoritarianism of the state, this was indeed a transformative moment in the history of knowledge production in Turkey (Öncü 2002).

Only recently do we observe publications that mention the presence of people who do not belong to the Kraepelian tradition and who resisted to the paradigm of Mazhar Osman. One such figure is İzzeddin Şadan. In chronicles on the history of psychiatry, Şadan appears as the total “stranger”¹⁹. According to Tunaboğlu-İkiz, Şadan challenged the predominant Kraepelian approach to psychiatry and wanted to apply the ideas of Freud, Brill, Jones and Jung regardless of the inconsistencies among these theoretical approaches (Tunaboğlu-İkiz 2010: 133). She goes on to emphasize how Şadan was excluded from the medical community and eventually left his position at the university hospital because of his challenges to the dominant school of thought and the charismatic leader of the psychiatric practice, Mazhar Osman²⁰. Kayaalp interprets the position of Şadan as that of the “bad seed” in constant conflict with Mazhar Osman. In a way, Şadan was representative of a new psychiatry, which could not find its voice in the collectivism of the modernization project. The organic view of mental illness and positivism combined with the predominance of the Kraepelian school left little room for the diffusion of psychoanalysis.

¹⁹ Here I employ the Simmelian concept of the stranger to make sense of the structural position of psychoanalysis in Turkish psychiatry.

²⁰ It is interesting how the revisionist historians of psychiatry in Turkey have unanimously invented İzzeddin Şadan as a marginal figure who nonetheless resisted the Kraepelian tendencies of the time singlehandedly. He is embraced as the significant symbol of the origins of Freudianism and psychoanalytic thinking in Turkey.

Even though the biomedical approach of Mazhar Osman and the dominance of the Kraepelian tradition are important in the failure of psychoanalytic theory to thrive in Turkey, I would argue that these should be interpreted not as the causes of its failures but symptoms of a larger dynamic at work. Historically psychoanalytic theory was a true hybrid incorporating but not fully integrated in the university, the clinic, literature and social theory. Hence, it needed to create its own space at the margins of various disciplinary boundaries and communities of knowledge. The capacity of psychoanalysis to translate across these culturally defined boundaries was made possible by its structural position. In the Turkish case, psychoanalysis could not enter the social imaginary through the medical psychiatric circles but had to be domesticated by the literary circles before it could be institutionalized.

Ultimately, it was the predominance of a structure of institutionalization that left no space for individual therapy to flourish²¹. That the hospital was the main location for care meant an increasing medicalization of mental health and the domination of the biomedical model. It was almost impossible for psychoanalytic thought to penetrate this structure. Another important factor was the lack of international scientific networks that would foster the development of psychoanalytic thinking in Turkey. The only possible link Izeddin Şadan was ultimately an outlier and could not bring the two communities together.

²¹ Keller also notes the lack of interest on the part of the psychiatrists to engage with the local population as a possible reason for the failure of psychoanalysis. Güvenç Salgırlı also notes this could be true for the Turkish case as well.

1.3. MENTAL RETARDATION AND THE HISTORY OF SPECIAL EDUCATION

The history of psychiatry was not conducive to the emergence of autism as a diagnostic category as I have shown above. The institution based treatment models as well as the relatively late introduction of the dynamic model and general skepticism towards individual therapy were important impediments in the development of finer distinctions between various developmental problems. However, psychiatry was not the only profession that was concerned with the mental well being of children. There were other institutions including the Child Protection Agency and the Guidance and Rehabilitation Centers.

The Child Protection Agency had its origins in the Ottoman Empire and it functioned as an independent charity until 1937 when it was designated as a public foundation. The primary purpose of the foundation was to protect children that were classified to be at risk. Even though this definition went through some changes historically, it was meant to cover orphans including those with disabilities, children who lived in poverty, abandoned children, “street children” and children at risk of engaging in criminal activities. While the Child Protection Agency assumed most of the responsibility in caring for “children at risk”, there were no systematic efforts on the part of the state to institute a systematic national protection program. Originally, the agency was not responsible for the care of children with disabilities (except for those covered under the Law for Children at Risk). However in 1983, the Law on Social Services and the Agency for Child Protection was passed which divided the responsibility of the care for children with disabilities between two institutions: the Ministry of National

Education and the General Directorate of Social Services and Child Protection Agency (Vural and Yücesoy 2003: 152).

Historically, the problem of children with disabilities including those with mental retardation has been treated within educational institutions. Education was a crucial tool in the formation of the new nation. According to Kaplan, “(r)aising the new generation of children as the *raison d’etat* is closely linked to perceiving youth as a preparatory phase to adult citizen life, as the object of the historical destiny of a nation, and as the subject of the political vitality of the state” (2006: 10). The function of education was not limited to instilling “nationalist identities” in the children of the newly formed nation, but it also served as a means to widen the net of the surveillance of childhood. As the rate of schooling increased, “child poverty” emerged as an important problem of the 1930s and 1940s (Karatay 2007: 166). While this remained an important area of focus, children with disabilities had to wait for another decade before the state introduced legal provisions for the regulation of special education. In 1950, the private İzmir Sağırılar Körler Okulu (Izmir School for the Deaf and Blind) was transferred from the Ministry of Health and Social Aid to the Ministry of National Education (Melekoglu, Cakiroglu and Malmgren 2009: 289). This is interpreted to be an important moment for the history of special education for after this period, the issue of disability was considered to be an “education problem” and not a “health problem” (Akçamete 1998).

In 1955, “Psikolojik Servis”, a center for the detection and diagnosis of children with special needs was established in Ankara (Öz 2012). This was to be the original basis of what was later named Rehberlik ve Araştırma Merkezi (RAM) or the Guidance and Research Center. Especially in the aftermath of the Marshall Plan, there were

multiple cooperative projects with education specialists in the United States. The Primary Instruction and Education Law (No.222) came into effect in 1962 and stated that schools and classes must provide accommodations for children with special needs (Melekoglu, Cakiroglu and Malmgren 2009). Despite these developments, special education provision for children with mental retardation was extremely limited. For example, in 1975, there were no children with mental retardation receiving special education in public institutions. According to Çağlar, there were about 500 children receiving special education services from schools run by private foundations. The rest of the children “were left on their own or at the responsibility of their families” (Çağlar 1976a: 477).

It is important to note that classification of children with mental retardation was a primary concern of education experts especially after the 1970s. A brief survey of publications on special education in the 1970s proves that one of the main concerns of the period was to identify those with “transient mental retardation” and make sure they are not placed in the same educational surroundings with those suffering from “real mental retardation” (Çağlar 1976b). Even though the Binet Simon Test of Intelligence was translated in to Turkish in 1915, work in this area gained full force by the early 1970s. In that decade, 13 tests of intelligence and cognitive skills were developed or adopted in Turkey including Kahn Intelligence Test, Stanford Binet Intelligence Scale and Wechsler Intelligence Scale for Children (Gülgöz and Kağıtçıbaşı 2004). IQ testing was a major part of the classification efforts. Children were classified into three groups: Slow learners (IQ score between 75 and 90), Educables (IQ Score between 50 and 70) and Trainables (IQ Score between 25 and 49). The special education programs were

designed to include those with IQ scores higher than 50 up until the 1980s (ZİÇEV). Those with severe mental retardation were excluded from education programs (Çağlar 1976a).

Child psychiatry was curiously absent from the history of children with mental illness. Guidance and Research Centers staffed by education experts worked in collaboration with schools for the detection and classification of children with mental retardation and children with behavioral problems. This could be explained by the absence of any systematic institutionalization of children in Turkey.

1.4. CONTEMPORARY ORGANIZATION OF MENTAL HEALTH CARE IN TURKEY

The structure of mental health care in Turkey provides a peculiar puzzle when compared to similar structures in Europe. It is characterized by an extremely centralized system where care is concentrated in the three main cities and particularly the psychiatric hospitals and the psychiatric units of general hospitals. The crucial defining factor of the Turkish field is that the majority of psychiatric care is hospital based and the field is characterized by the predominance of the psychiatrists. The mental health sector consists of professionals including psychiatrists, psychologists, psychiatric nurses, social workers and counselors.

Turkey is also one of the few countries in Europe where there has been an increase in the number of psychiatric beds over the last decade²² (European Commission EUROSTAT 2010). While the number of private hospitals grew 48% between 2002 and 2008, this growth has not been reflected in the field of mental health care (Ministry of Health of Turkey 2008: 43). According to Yanık, the reluctance of the private sector to invest in mental health hospitals could be explained by inability of the population to afford private care, insufficient state subsidies and the stigma attached to undertaking a project in this field (Yanık 2011: 54).

The provision of health care is provided by hospitals of the Ministry of Health, University Hospitals, and hospitals of the Ministry of Defense. There are also private hospitals owned by individuals or foundations as well as hospitals run by minority foundations (Duygun et al. 2007). According to Ministry of Health Statistics, there are 1439 hospitals in total of which 843 are run by the Ministry of Health, 62 by the universities and 489 are private. Out of these hospitals, only 12 are psychiatric hospitals, 8 of which are public (Ministry of Health of Turkey 2010). Children and adults can also receive psychiatric care from general hospitals but this is often acute care and does not involve long-term psychiatric care as is typical at the psychiatric hospitals. There is however, rehabilitation services for children with severe mental retardation provided by the Social Services and *Child Protection Agency* since 1983 (Vural and Yücesoy 2003). As of March 2012, there were a total of 4,793 children receiving full time residential care at these centers, 4,051 of which were diagnosed with mental disability. While this number has grown substantially since 2000 when only 1,476 children were receiving

²² The others are Austria, Bulgaria, Germany and Norway.

therapy at these centers, they are still not a significant provider of care and serve only a small portion of children suffering from mental disabilities²³.

1.5. DIAGNOSIS AS CURRENCY AND THE POLARIZATIONS IN ACCESS TO CARE

New social policies introduced by the Justice and Development Party (Adalet ve Kalkınma Partisi) in the last decade have transformed the field of disability. These new amendments as outlined in the Turkish Disability Act of 2005 have increased the benefit level of disability allowances and introduced an at-home-care allowance for a family member who will be the caregiver for the disabled individual for eligible families. As Yılmaz argues, as a result of these changes, “the disability category became quite important not only for disabled people but also for poor households in general, because it has become a state-guaranteed channel to formal employment for disabled people and a regular income source for poor households which have a disabled member” (Yılmaz 2011). In addition, the state which until then had subsidized therapy, special education and rehabilitation for those covered by the social security system and their families, extended this right to all children with special needs regardless of social security.

A major site for the evaluation, definition and classification of disability in Turkey is the hospital where individuals need to appear before a medical board to receive a report certifying their disability. This report plays a crucial part in the formation of “disabled subjectivities”. It is only after the assessment and after receiving the medical

²³ Çokkazan, Ali. 2012. Telephone Interview by author, Ankara. May 4.

report that one is eligible for disability benefits. The certification is dependent on the medical assessment that measures the degree of incapacity. In response to the demands of the European Union, Turkey began a reformulation of legal and social policies regarding disability. A crucial development that led to the reconfiguration of disability taxonomies was the adoption of the Law on Persons with Disabilities in 2005, the first disability specific law (Gül 2007). According to this new legislation,

a person with disability is any person who has difficulties in adapting to the social life and in meeting daily needs due to the loss of physical, mental, psychological, sensory or social abilities at various levels by birth or by any reasons thereafter and who therefore needs protection, care, rehabilitation, consultancy and support services²⁴.

Who can claim to be disabled? Who has the expertise to differentiate the disabled from the able bodied? The new law was crucial in the reconfiguration of disability as it introduced a global classification system in disability assessment, the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF). In 2006, the Regulation on Disability Criteria, Classification and Health Board Reports for Persons with Disabilities was declared which introduced a new calculation formula and led to the reformulation of the definition of disability (Yılmaz 2011). The adoption of IFC criteria meant the insertion of a new kind of apparatus for the "production, circulation, accumulation, authorization and realization of truth" (Rose 1996a: 45). The introduction of new technologies and practices geared towards a "true"

²⁴ Law on Persons with Disabilities, No. 5378, Article 2 (a), adopted on 1 July 2005

definition of disability served to exclude a considerable number of disabled people from access to disability benefits.

The International Classification of Functioning, Disability and Health was developed to improve upon the older system which was based on the medical model. This new system of classification “seeks to locate an understanding of disability at the intersection between the biological body and social and institutional structures” (Imrie 2004). In the definition of disability, while the ICF introduced a new system of calculation of impairment, the requirement of a diagnosis of at least 40 percent loss of body function as determined by the medical boards stayed in place. These regulations include the provision of identity cards for people with disabilities, employment under the quota system, provision of special education as well as eligibility for the disability allowance and cash for care benefits (Gül 2007). Under the formula, some applicants lost their eligibility because they received a lower percentage. This led to a reclassification of a large group of people who were classified as disabled under the old system to be classified as able-bodied (Bezmez May 16, 2010; Yılmaz 2011).

According to Yılmaz, the social policies for the disabled adopted by the Justice and Development Party can be summarized under three main headings: increased fines for employees who refuse to meet the quota for the employment of people with disabilities, increased levels of disability allowances and the introduction of cash-for-care benefits (Yılmaz 2011). Typically, cash-for-care benefits are introduced in advanced welfare states to replace the provision of services in kind and involve cash payments to allow recipients to choose the kind of care they prefer. The underlying rationale in this transition is the transfer of responsibility to the user and the caregivers (Arksey and

Kemp 2008: 8). In the Turkish context, the adoption of at home care allowance was a means to legitimate informal care, or the care of the disabled person by a family member by providing income support in the amount of minimum wage. This is an extension of the official policy that depicts the family as the main caregiver of the disabled (Aysoy 2008; Oğlak 2008). According to Yılmaz, as a result of these changes “the disability category became quite important not only for disabled people but also for poor households in general, because it has become a state-guaranteed channel to formal employment for disabled people and a regular income source for poor households which have a disabled member” (Yılmaz 2011). The degree and percentage of impairment as defined by the medical boards constitutes the main space of contestation in the disability field. They do not necessarily problematize the medicalized definition of disability. Instead, their criticisms are directed towards the calculation of percentages and the way in which the assessments take place.

1.6. CONCLUDING REMARKS

Bakırköy Mental Health Hospital remains the most important center of psychiatric care in Turkey. In order to understand the significance of Bakırköy in the Turkish health system, it will suffice to glance at some figures. With 1,631 beds, it is the hospital with the highest number of beds not just among mental health hospitals but among all the hospitals in Turkey (Ministry of Health of Turkey 2009). This emphasis on hospitalization, the use of psychopharmaceuticals and electro-convulsive therapy is significant in several regards. First of all, as I argued above even though there has been

an emphasis on incarceration and institutionalization since the early years of the Republic, this has never been achieved at a national scale.

The underdevelopment of institutionalization effectively means that turkey has never experienced a large-scale deinstitutionalization. This has important consequences for the organization of mental health expertise in Turkey as well as the categorical understandings of mental diseases. On the one hand, psychiatry never lost its authority to diagnose and treat mental illness. The strong hold of the profession has in fact resulted in the recent limitations over the capacity of psychologists to diagnose and treat mental illnesses without the supervision of a psychiatrist. On the other hand, it has meant the predominance of mental retardation as an organizing category especially in the field of childhood disability. The wide scale introduction of Attention Deficit and Hyperactivity Disorder and Autism Spectrum Disorder are relatively recent and the category of Developmental Disability has not been adopted extensively by the clinical staff or by parents. This could partially be explained by the absence of any nationwide system of surveillance of childhood mental health or early intervention. In fact, the system is characterized by a divide between retardation that could be accommodated either in the family or at school and institutionalization. Often this divide is blurry and there is a tendency to use high dose pharmaceuticals to make sure the child could be cared within the extended family network.

Secondly, the meanings of normalization have taken different forms with each new government. This point will be discussed in more detail in the following chapters but suffice it to say that the current government, which actively supports normalization through mainstreaming often, does so with a purpose to privatize and outsource the

rehabilitation and care of children and adults with disabilities. As I show in the following chapters, the story of autism in Turkey is only meaningful if we understand it as a juxtaposition of psychiatry and mental institutions with special education and mental retardation.

Chapter 2

A Disorder Without a Name: Diagnosing Autism at the Hospital

“Autism is not a Turkish thing. It’s an American disease. There are no autistic children in Turkey”. This is what the founders of an autism organization were told when they met with state officials in early 2000. Things have come a long way since then. Not only does the state recognize autism as a separate disability category, but it has also begun to provide assistance in terms of special education and disability benefits for children on the autism spectrum and their families. How did autism become a Turkish disorder? How is autism localized? Who are the interpreters active in the transposition of autism to the Turkish context?

Before I left for Turkey to conduct fieldwork in 2009, I had read news articles on the impending autism epidemic in Turkey, I had heard of autism organizations such as the TOHUM Foundation²⁵, and I had seen the famous media campaign to raise autism awareness. Having also conducted research on autism in Boston and New Jersey, I expected to find strong parent organizations, a field of autism therapies that was just starting to emerge and multiple “global” experts who were engaged in translating autism

²⁵ This is the foundation behind the public awareness campaign as well as many other autism advocacy projects including a school for children on the spectrum. I will discuss the position of this foundation on the field of autism advocacy and civil society in general in the following chapter.

to the Turkish context. Instead, the field of autism that I found was reflective of growing concerns over the dissolution of the extended family networks, the demands of the European Union, professional struggles and the looming danger of the “uneducated child”. The diagnosis, interpretation and representation of autism is embedded within the social fabric of a locality. As I show in the rest of this chapter, a study of autism enables us to explore the contemporary moral landscapes and the shaping of difference and disability in Turkey.

As I argued in the previous chapter, the Turkish field of mental health care is highly divided. Historically child psychiatry has positioned itself as the provider of services in mental illness and has shied away from issues of intellectual disability and developmental disorders. Psychologists and education experts have assumed expertise in the detection and treatment of developmental problems. This division of labor has important consequences for the ways in which autism is problematized in contemporary Turkish society. In an effort to understand the “moral career” of the autism patient, this chapter shifts the focus to trace this journey, which begins at the university hospital’s child psychiatry clinic and continues on to various medical, psychological and educational assessment and therapeutic programs. While not taking a position of arguing that autism is socially constructed, I will show that the institutional matrix determines the type of autism diagnosis that a child gets. I will show how the child psychiatrists, while claiming sole authority to diagnose autism have marginalized themselves from the field of autism therapies and special education.

One major difference between the United States and Turkey was the ambivalence surrounding the diagnostic process in Turkey. During the six months I spent in the field, I

observed hours of diagnostic and follow-up sessions at the hospital and met many parents whose children were on the spectrum. However, among these children that I met only some of them had received an official diagnosis of autism²⁶. Most of them had received various labels ranging from “atypical autism²⁷” to “impairments in social communication”. Even though the parents had accepted their children as autistic and the psychiatrists and the therapists were treating these children as they would any other child on the spectrum, there was a mismatch between what the child received as an official diagnosis and what got communicated to the parents. More significantly, the diagnostic process showed differences for children coming from divergent class backgrounds.

As I argue in the rest of this chapter, multiple factors were influential in the creation of this *disorder without a diagnosis*. Even though the psychiatrists were trained to use the Diagnostic and Statistical Manual of Disorders (DSM), there was general mistrust against it. “It is an American invention”, one psychiatrist told me in a dismissive way. The idea of an autism spectrum made up of a range of impairments and a variety of conditions had not been successful in Turkey. While the DSM specifically classifies autism as part of a spectrum, autism was localized as wavering between severe cases (reminiscent of mental retardation) and mild cases (bordering on normal). How did this binary system come about?

I identify two divergent paths in the formation of this binary system. On the one hand, lower income families with children exhibiting developmental problems consult the

²⁶ See Appendix Two for the Autism Spectrum Disorder entry of DSM-IV-TR.

²⁷ Even though atypical autism is used to refer to Pervasive Developmental Disorder- Not Otherwise Specified, this relation remains ambiguous during the diagnostic sessions. Parents often take this diagnosis to mean something other than autism.

child psychiatry or neurology clinic of a university hospital. These hospital clinics are organized in such a way as to evaluate as many cases as possible in a short amount of time. In fact, after an initial interview with the resident, the child psychiatrist has ten minutes to evaluate the condition of the child, identify the problem, make the diagnosis and plan a treatment program (Yazgan May 6, 2012). According to one psychiatrist who administers longer standardized diagnostic sessions at a university hospital in Ankara, most families bring their children to her after having seen an expert previously and having received a diagnosis. She explains that they come to her to “strengthen” the diagnosis and they ask her how the psychiatrist could give a diagnosis in five minutes.

Due to overcrowding at the hospitals and state mandated quotas for the number of patients to be seen each day, there is rarely any opportunity to fully evaluate the condition of each child. Often the family leaves either without any specific diagnosis or a diagnosis on paper, which is not fully explained to the family. The final diagnosis is not entirely relevant for the outcome because the determining factor is the percentage of impairment as determined by the medical board of the university. The extent of disability is crucial in determining eligibility of entitlements including special education and disability allowance. The child diagnosed with autism, atypical autism or mental retardation may be eligible for the same kinds of services as long as he is found to have the same extent of disability²⁸. The state provides funding for a total of 12 hours of special education per month with 8 hours devoted to individual instruction and 4 hours for group work.

Children diagnosed with autism, atypical autism or mental retardation are all eligible for

²⁸ While the percentages associated with these disorders differ from each other, the final percentage is calculated on the basis of a formula that combines various impairments. Hence, the child may receive the same percentage even with different diagnoses.

these services. However, institutions, which provide this therapy/education have almost no expertise with children on the spectrum. Often children with mental retardation follow the same educational program as those on the spectrum. Hence, a diagnosis does not guarantee therapy for longer hours nor individualized therapy specific to children on the spectrum.

On the other hand, middle class parents with children who exhibit developmental problems may or may not take their child to the university hospital. After consulting the child psychiatrist, some parents do not even continue with the disability assessment because of the fear of labeling and stigma. Often they prefer to have their children followed by psychiatrists in private practice. For children who do not exhibit severe symptoms, the physician often says there are symptoms of developmental delays which may disappear with therapy. The family is then referred to a private therapy center where the child receives intensive behavioral therapy and may eventually be mainstreamed. The crucial finding that differentiates the Turkish case from what is observed in the United States is that middle class parents allied with the therapists working in private practice and opted out of the autism network. Instead of pushing for more legislation and awareness in autism, middle class parents try to normalize their children and lose the diagnosis. In this chapter I will show how the autism spectrum was disassembled and autism was transformed into a disorder without a diagnosis.

This chapter begins with a review of literature on transnational studies of autism. While recognizing differences in the diagnosis, etiology and meanings of the illness across the globe, these studies posit that an autism diagnosis brings the experience of the illness closer to the Western experience particularly through the expansion of DSM

categories. This a problematic conclusion as can be observed through the Turkish case where in the absence of the particular institutional make-up that gave rise to the “autism epidemic” in the West, the experience and the reactions diverge from those studied in other parts of the world.

I then provide a discussion of the early work on autism in Turkey paying particular attention to changing approaches to developmental disorders in the history of child psychiatry. The following three sections draw from fieldwork data and present an analysis of the clinical encounters that take place at the university hospitals²⁹. I argue that psychiatric diagnoses serve a particular function in the Turkish context. In the absence of a marketplace for therapies and the failure to secure the alliance of parents, the autism diagnosis carries no inherent value. The psychiatrists have internalized a type of “bleak approach” with regards to autism and are hesitant to pronounce the diagnosis. Instead, they choose to follow a method of “managed confinement” through the use of pharmaceuticals. Getting a diagnosis at the hospital for a child with special needs then turns into a performative game of negotiation because different labels and different percentages as assessed by the medical committee are crucial in a family’s eligibility for disability allowance. Often the family tries to claim additional losses through various impairments sometimes with the support of the physician.

In the next section, I show how a discourse of science dominates the field of biomedical therapies. Interestingly, it is this adamant belief in positive science that has

²⁹ This chapter focuses solely on the experience of the families at the hospital, most of whom are lower class families, some with rural backgrounds. In chapter 3, I will present findings from fieldwork conducted at private clinics and show the divergent experiences of middle and upper class families.

led parents to search for cures in non-medical behavioral therapy –which are advertised to be scientifically proven- and biomedical therapies –which have no proven scientific effect in reversing the symptoms of autism and are shunned by the medical establishment as alternative therapies-. I will argue that unlike the American case, where parents look for “whatever works” for their child, in the Turkish case, the parents are still confined in an institutional matrix that wavers between a miracle cure through biomedical intervention or normalization through behavioral modification. There is no space for recognizing neurological differences. In the last section, I will argue that an understanding of autism and childhood pathology in general is deeply embedded in changing conceptions of family and motherhood in Turkey. As women increasingly join the workforce, children are left with “strangers” either through childcare centers or with nannies. Migration to cities has greatly limited the availability of extended family member who can care for the child. Mothers attributed the onset of autism to having abandoned their historic role of preparing future citizens. In a strange twist, having been incorporated into the world of autism and disability, they now had to learn how to be mothers again, this time to raise “autonomous” children.

2.1. AUTISM ACROSS THE GLOBE

As I argued in the Introduction, the debate on the diffusion of Western mental health categories sparked by Watter’s publication of *Crazy Like Us*, has centered on the loss of diversity in the experience and treatment of mental disorders in non-Western contexts. However, as I show in the rest of the chapter, the more significant question is how

diffusion occurs. It is important to recognize that the trajectory of a diagnostic category is contingent upon the local relations of expertise, organization of care as well as state society relations. In transcultural studies of autism, researchers have identified the ways in which different cultural and social environments have an effect on the ways in which children on the spectrum are identified, classified and treated.

Some of these studies focus on the cultural differences in the diagnosis and management of autism. For example, Grinker (2007) follows the spectrum to South Korea, South Africa and India and argues that families and experts in these setting work with different explanatory models, meanings and different classifications. A recent cross-national study of autism in Israel, South Korea, United Kingdom and the United States has also identified differences in symptom expression in several relevant areas across local contexts (Matson et al. 2011). Similarly, in her study of developmental disorders in India, Daley (2003) has found that the age at which parents recognize symptoms as well as the type of behavior that they notice first differ from that observed in Western contexts. A study in Saudi Arabia has uncovered gender differences in when children receive the initial diagnosis (Al-Salehi and Al-Hifty 2009). In a comparative study of children with autism, researchers found differences in age of noticing abnormality, age at diagnosis and age at the start of intervention as well as techniques of intervention between a sample from Saudi Arabia and that from Egypt (Hussein, Taha and Almanasef 2011). An Iranian study based on the results of a national screening project reports the lower prevalence of autism in Iran and suggests that, among other factors, this could be explained by the reluctance of parents to accept a stigmatizing diagnosis which leads to under-reporting of behavioral problems (Samadi, Mahmoodizadeh and McConkey 2011).

While these findings are crucial in revealing the cultural differences in the detection of autism, they take the diagnostic category as a fixed entity. By working with a predefined category of autism, these studies fail to effectively address the cultural and institutional mechanisms, which may be giving rise to these divergent findings.

Other studies have highlighted the cultural interpretations, moral meanings and subjectivities that are assembled around autism. Anthony (2009), for example, has demonstrated that what is classified as problem behavior such as failure to establish eye contact or preferring to play alone, often leading to help seeking behavior by the parents in the West is not necessarily interpreted as abnormal in Ghana. A study of the NGO Action for Autism in New Delhi illustrates the particular images conjured by autism in a context where masculinity is a crucial component of the local culture often leading to behaviors of infantilization and feminization among the care givers (Mehrotra and Vaidya 2008). In a comparative study of Italian and Cuban families, significant differences in parental attitudes were identified (Sotgiu et al. 2011).

While most of these studies identify cultural differences in parental cognition of the disorder, presentation of symptoms and beliefs about etiology, there is a general consensus that the universalization of the diagnostic category is bringing the experience of the illness closer to its Western model (Daley 2003). The changing landscape of disability in the non-Western world, particularly the increased provision of services for children on the spectrum are invoked as possible ways in which the Western model is replicated. According to a recent article, for example, diagnosis and treatment of autism in the non-west provides successful examples of the incorporation of the American system of mental health (Sarrett and Kushner 2011). In this chapter, I show that the local

contingencies of the Turkish case such as the absence of the experience of deinstitutionalization, underdevelopment of a field of therapies and the reluctance of parents to assume an active role in lobbying for their children have resulted in divergent results.

2.2. EARLY WORK ON AUTISM IN TURKEY

Children, particularly the health of children has been an important space of intervention for the Turkish state since its inception. The “problem of the child” has come to mean many diverse things such as street children, children living in poverty, the dangerous child, abused children, orphans etc. The mental well being of children was limited to work on mental retardation and emotional problems. In the short history of child psychiatry (an independent field since 1959), the diagnosis and treatment of children with developmental delays was not considered a priority. In the early years, the emphasis was on identifying neurological or psychotic conditions. Possibly influenced by its close connections to adult psychiatry, the field was interested in discovering the etiology of diseases. A review of articles published in the journals *Child Neuropsychiatry and Guidance* (1968-1971) and the *Archives of Neuropsychiatry* (1964-1974) shows that the emphasis was on pharmaceutical interventions with a growing influence of dynamic psychiatry. Mental illness was believed to be closely connected to the affective environment provided by the family, particularly the mother and “change in the mental health of the child is produced by the disturbance of this intimate relationship” (Ergun 1967). As I argued in Chapter One, child psychiatry was interested in mental retardation

only as a medical curiosity and there were almost no efforts in designing effective interventions in this area.

The first time autism is mentioned in the literature is in an article on childhood schizophrenia published in 1971. From this article, we learn that the authors, while recognizing the importance of genetics still mention the importance of the “affective environment” of the family in explaining the disease. We also learn that the intervention techniques are a combination of psychoanalytical techniques, special education methods and the use of psychopharmaceuticals. According to the authors “the stages of therapy are the rupture of autism, a redirection of the therapeutic transference to the family, the elimination of the mannerisms and stereotypical behavior that makes the child asocial, the rerouting of aggression to group play and learning” (Cebiroğlu, Sümer and Aydoğmuş 1971).

The emphasis on the family should come as no surprise. The “refrigerator mother” theory had been a popular explanation method in the West. While childhood schizophrenia diagnoses are replaced by autism in the 1980s, autism remains a very rare condition and does not attract the interest of scholars until the late 1990s. In terms of academic research, autism still does not attract the attention of medical scholars. A keyword search on the Turkish Psychiatric index for autism and autistic yields the following results:

Table 1. Distribution of Studies on Autism

<i>Time Interval</i>	<i>Number of Articles Published on Autism Spectrum Disorders</i>	<i>Total number of articles</i>	<i>Percentage of articles on autism</i>
1975-1979	2	65	3%
1980-1989	1	386	0.3%
1990-1995	11	1265	0.9%
1996-2000	18	1673	1.1%
2001-2005	41	2182	1.9%
2006-2012	58	3698	1.6%

Source: *Türk Psikiyatri Dizini*, <http://www.psikiyatridizini.org>

In Turkey, early work on autism has been conducted at the Autism Diagnosis and Research Center at Ankara University, founded in 1989. The Center was affiliated with the Child Psychiatry Clinic founded by Mualla Öztürk in 1974, a child psychiatrist trained in the United States. According to child psychiatrists who were actively involved in the foundation, children were initially diagnosed based on the criteria developed by Kanner. After the publication of DSM III (1980) and DSM III-R (1987), these classifications were used during clinical evaluations (Akçakın and Kerimoğlu 1993a). This could partially explain the rise in autism diagnosis in the 1990s since the DSM criteria was more inclusive than that of Kanner's. According to Akçakın, the total number of children diagnosed with autism at the center between the years 1976 and 2003 was 1,200. While they were in the process of digitizing the medical records and did not have an exact number, she estimates that up to 3,000 children have been diagnosed at the center since its foundation³⁰. Considering that this is one of the major centers to get an autism diagnosis, this number is very surprising. Also significant is the fact that this

³⁰ Akçakın, Melda. 2012. Personal Interview by author, Ankara. September 24.

hospital serves not only the residents of Ankara, but more than fifty percent of children seen at the autism center reside in other cities. One possible explanation for the few number of children receiving the diagnosis could be problems related to the referral systems. According to a recent study conducted at the same center, of the 468 children who were diagnosed with autism, only 4% were referred to the psychiatrist by the pediatrician (Erden 2010).

Table 2. Ankara University Autism Center Patient Statistics

<i>Time Interval</i>	<i>Total Number of Outpatient Admissions</i>	<i>Total Number of Autism Diagnoses</i>	<i>Percentage of diagnoses</i>
Jan. 1976-Dec.1990	11, 440	44	0.4 %
Jan. 1991-Dec.1991	981	33	3.4%
Jan. 1992-Jan.1993	1141	42	3.6%

Source: Akçakın and Kerimoğlu 1993b

Therapy performed at the center during the early 1990s was inspired by behavioral therapy developed by Lovaas in addition to psychodynamically oriented play therapy (Akçakın and Erden 1993). Beginning in these early years, the emphasis has been on the development of language skills. This is possibly reflective of parental concerns over the delay in language³¹.

³¹ DeGiacomo and Fombonne have found that the most common parental concern in the West is speech delay followed by behavior problems while Daley has discovered social difficulties were more significant for Indian parents. See Daley 2003; DeGiacomo and Fombonne 1998 (DeGiacomo and Fombonne 1998). In my interviews I found that parents are more likely to be concerned about behavioral issues. However, the professionals often complained about parents' insistence on developing language skills.

2.3. NOT EVERY CONDITION NEEDS A LABEL: DISASSEMBLING THE AUTISM SPECTRUM

Having made contacts before my arrival in Istanbul, I walked confidently into the Pediatric Neurology department of a university hospital. I was going to observe the sessions of a prominent figure in the field who had published books and articles on autism. I had already conducted observations at The Autism Center at the University of Medicine and Dentistry of New Jersey in Newark so I assumed I knew what to expect. I wanted to learn about the use of instruments and tests for the assessment of autism³². I expected to find assistants or psychologists busy with administering the Autism Diagnostic Observation Schedule (ADOS)³³ or therapists working with children to “modify” their behavior. Instead I found about fifty families who had crowded the corridors waiting to be seen by the neurologist who spent only two days per week, a total of ten hours at the hospital. The sessions did not last more than 10-15 minutes. Sometimes he saw up to thirty patients per day. There was no possibility of administering any kind of test, let alone the ADOS, which usually lasts about an hour. In fact, these tests had not yet been translated or standardized in Turkish.

The preoccupation with diagnosis that was reflective of the American field of autism simply did not exist here. Neither the parents, nor the experts were interested in

³² A clinical diagnosis of autism is based on behavior. The diagnostic criteria listed in the DSM is used in finalizing a diagnosis.

³³ ADOS is considered to be the gold standard instrument for diagnosing autism. Through the use of different tools such as toys, the examiner provides opportunities for the subject to show behaviors that are deemed deficient in autism especially behaviors of social and communicational skills.

categorizing, labeling or diagnosing. The diagnostic categories were mentioned only as part of a negotiation between the psychiatrist and the family. In theory and in practice, the object of the diagnostic process is to correctly identify and classify the child's disorder, the pathology. Instead, the child psychiatrist or neurologist functioned as a middleman deciding on the best category that would benefit the child. The diagnosis was secondary to the percentage of functional loss that would be determined by the medical committee at the hospital. The families often tried to claim additional losses as a way to increase the percentage so that they would be eligible for more services. By law, the state is responsible for subsidizing 12 hours of therapy/special education per month. All children with special needs including those with developmental, emotional and behavioral problems are eligible to receive these services regardless of their diagnoses. The diagnostic session did not function to fix a diagnosis but rather to formulate a strategy for "collecting" the largest number of impairments so as to be eligible for disability benefits. More importantly, the psychiatrists were reluctant to give out diagnoses that might be especially stigmatizing and might ruin the child's chances for being mainstreamed in later years. This was particularly true for an autism diagnosis which "generates more fear" among families and teachers than mental retardation according to one special education expert. This statement was repeated by many of the families.

This reluctance to focus on diagnoses was an interesting finding since in Turkey, psychiatry as a profession has monopolized the authority to diagnose mental illness. According to Turkish law, among those working in the field of mental health, only those with a degree in medicine that is psychiatrists and neurologists have the right to officially

diagnose and treat autism spectrum disorders (and other mental illnesses and disorders)³⁴.

Psychologists, including clinical psychologists with a graduate degree in clinical psychology are not allowed to make official medical diagnoses. They can only work under the guidance of a psychiatrist. A major consequence of this has been an extremely hierarchical division of labor, particularly at the hospitals. Those with degrees in psychology, social work, guidance and psychological counseling are assigned routine tasks such as the administration of neuropsychiatric or psychometric tests or assistance in diagnosis through observation. The planning and administration of psychotherapy needs to be supervised by a psychiatrist. This is an important part of the professional struggle between psychiatrists and psychologists. In fact, this jurisdictional struggle had taken a new turn when in 2011 the Ministry of Health began to enforce this law more forcefully under pressure from the Turkish Psychiatry Association. The end result was the closure of many private practices run and staffed by psychologists. Despite the centrality of diagnosis to the professional identity of the psychiatric field especially given its close identification with medicine since early institutionalization efforts, child psychiatry experts were reluctant to build a profession that functions around classifications and labeling. Both in practice and in their narratives, they did not emphasize the diagnostic process³⁵.

³⁴ This is based on a ruling that dates back to 1928: Tebabet ve Şuabatı San'atlarının Tarzı İcrasına Dair Kanun No.1219

³⁵ This was true for autism as well as for mood disorders. Even though my research did not entail a systematic study of these other disorders, I have observed some sessions of children exhibiting other behavioral or intellectual problems. The only exception seemed to be Attention Deficit Hyperactivity Disorder (ADHD), which seemed to be more visible and common. This could be due to the fact that these children are often referred to the

There could be several explanations for the dismissal of the diagnostic process. The most obvious one was the experts' ambivalent relationship with the DSM. The publication of the revised version of the DSM in 1980 was a move to increase the reliability of psychiatry through the adoption of standardized disease categories in order to bolster the profession's claims to scientificity. However, this shift had some unintended consequences. According to Whooley, on the one hand, the DSM made psychiatric practice more "transparent" to others including patients, insurance companies, hospital administrators, other organizations and mental health care workers. The transparency of psychiatric expertise has resulted in a loss of autonomy for the profession. Whooley argues that in order to restore their autonomy, psychiatrists have come up with various strategies or "workarounds" including fudging the codes on official documents and negotiating with patients (Whooley 2010). This also explains why the Turkish psychiatrists were reluctant to embrace the DSM as they engaged in a jurisdictional struggle with the psychologists. The standardization brought with the DSM could have resulted in the inclusion of psychologists in the diagnostic process, which would have greatly diminished their authority. Instead, the psychiatrists emphasize the importance of the clinical encounter with the patient and do not want to be portrayed as simply following a checklist of symptoms in determining the disease category.

There is a similar dynamic in the Turkish case particularly with respect to the assessment of eligibility for disability benefits. Psychiatrists employed several

child psychiatrist by the school and the expectation of a diagnosis is already built into the school report as well as communicated to the parents. Autism, on the other hand, can "fly under the radar" simply because it does not involve the school to the same extent as children begin to exhibit problems before they begin school.

“workarounds” in their efforts to get the children in state subsidized special education. However, this was often done in negotiations with the patients since an autism diagnosis might effect the child’s inclusion in integrated education.

On the other hand, the aversion towards the DSM in Turkey is also permeated with hostility towards the dominance of the Western biomedical model as exemplified by manual. On several occasions, the psychiatrists and therapists dismissed the DSM as a form of American cultural imperialism. According to one psychiatrist, for example, the DSM “labels the individual, freezes the disorder and turns it into a stigma”. This scornful attitude towards the DSM does not translate into a dismissal of the expanding influence of psychopharmacology, which is also interpreted as part of American hegemony³⁶.

Instead, biomedical solutions to mental disorders are widely embraced and psychiatrists including those who come from a psychoanalytic background often use medication to “manage” diseases. The follow up sessions work as a means to sustain what I call “managed confinement”. While the responsibility of care has shifted from the institution to the family, this does not necessarily mean more opportunities for socialization. Despite the recent governmental initiatives to create more opportunities for inclusive education, it is estimated that most of the children on the spectrum do not attend any form of schooling³⁷. This is particularly true for families who live in rural areas. In

³⁶ For a similar case in Argentina see Lakoff (2005: 61)

³⁷ TOHUM Autism Foundation estimates that only 10% of children with autism attend formal education (Tohum Otizm Vakfi 2010a). While there are no systematic studies on the rate of schooling for children on the spectrum, an important indicator is the difference between the number of children who receive an educational diagnosis of autism at the Guidance and Research Centers and the number of students receiving formal education. For the 2008-2009 school year, there were 2,582 students enrolled in primary and

addition, due to the stigma attached to having a child with special needs, most families choose to keep their children at home. These families need medication to contain the behavioral problems they experience with their children. Middle class families, on the other hand, use the medication to further help their child “normalize”. Various medications are used for increasing the child’s attention span, decrease behavioral problems and improve eye contact so that the child can benefit more from therapy and eventually be integrated in mainstream education.

In fact, this ambivalence towards fixing a diagnosis is symptomatic of the way autism is understood and treated in Turkey. The object and goal of psychiatry in approaching autism is not to classify or identify pathology but to manage symptoms. As one psychologist working at a university hospital put it: “It is not really in my interest to give a diagnosis. If you know what you need to do, you don’t need a diagnosis”. According to the president of the Center for Autistic Children at Ankara University, psychiatrists do not give definitive diagnosis for children under age three.³⁸ Part of the reason is a strict adherence to DSM criteria, but this could also be explained by a reluctance to categorize the child in a specific diagnosis. He goes on to say that these

secondary schools including special education classrooms and integrated education. However, the number of school- aged children who had received an educational diagnosis of autism in 2009 were 10,811 (Tohum Otizm Vakfi 2010b: 15). Based on these numbers, the schooling rate is 24 percent. However, considering that many children go undiagnosed particularly in rural areas, the rate of schooling for those with autism is probably less than this.

³⁸ This is similar to what was practiced in the US in the past since DSM-IV criteria for Autism Spectrum Disorders were defined for children 3 years and older and the reliability of these criteria for younger children was not established. However, as early intervention is increasingly recognized as essential for the treatment of Autism Spectrum Disorders, the age of diagnosis has been going down.

children could be exhibiting communicational problems because of lack of stimulation. “These could be babies who did not receive much attention or they could have spent too much time in front of the television” (“Bebeklerde iletişim” 2007). In fact, some families whose children exhibited language delay have been instructed to wait for a diagnosis and simply “stimulate” their children in the hopes that they might begin to communicate more effectively. A study of children who consulted the outpatient psychiatry clinic in Istanbul gives more concrete clues on the workings of diagnostic practices. According to this study (N=1,028), the most common complaints were language delay (18.4%), anxiety (17.1%), behavioral problems (13%) and hyperactivity (13%). Based on these complaints, one would expect the diagnosis of autism and ADHD to be dominant among this population. However, the majority of these children were diagnosed with adjustment disorder (16.2%) while the next common category was ADHD (14.8%) and only 2.5% were diagnosed with autism (Abalı et al. 2006). It is not possible to deduce that children diagnosed with adjustment disorder would, with the use of other assessment tools, be diagnosed with autism spectrum disorder. However, it could point to a different use of adjustment disorder as outlined in DSM-IV, which outlines an “identifiable stressor” that results in the presentation of symptoms.

As I argued in Chapter One, psychiatrists have been able to defend their jurisdictional authority historically by simultaneously rejecting the power of traditional healers while at the same time integrating the “charisma” of the wise man to their profession. In addition, they have allied with the modernizing elite in designing and implementing the social engineering projects of the early Republican years. One significant way in which this relationship has surfaced is through the use of confinement

as the main technique of managing mental illness. This did not result in large-scale institutionalization, however. Confinement often meant domestic confinement and care by the extended family. Despite their reluctance to diagnose or treat at a large scale by getting involved in mechanisms of child surveillance, the child psychiatrists have enjoyed a long period of authority precisely through this relationship with the state. Families still take their children to the child psychiatrists first when they suspect something is not right. According to a recent study at two hospitals in the southeast, 91.4 percent of the parents of children with cognitive disabilities consulted a child psychiatrist first (Bayhan and Sipal 2011).

The unwillingness to engage in a thorough diagnostic process could also be explained by the lack of interest in rigorous academic study. DSM criteria is an essential part of academic research and “a DSM diagnosis is not much use if you are not going to use it to publish” one psychiatrist explained. The practice, particularly at the hospitals, is not conducive to collecting data for research. In addition, most of the diagnostic tests that are used in the diagnosis of autism are not translated into Turkish. The translation, adaptation and the assessment of reliability and validity of these tests is an important part of the task areas of psychologists³⁹. They are not only responsible for administering the tests but they are also in charge of making sure the tests can be used in Turkey. However, as of recently there was not much interest in the local adaptation of tests used in the diagnosis of autism. So far only two screening tests, CHAT and M-CHAT have been adopted as a result of the initiatives of the Autism Foundation. The purpose of these tests

³⁹ The adaptation of psychological and educational tests provide most of the focus of graduate work at the psychology departments.

is not necessarily to help in diagnosis but to aid primary physicians as well as pediatricians with early diagnosis.

The classification of disability has also been changed, which has effectively excluded some individuals who were previously eligible for disability benefits. In addition, state aid is contingent on the economic status of a family. A diagnosis of autism or atypical autism enables the child for 12 hours of state subsidized therapy per month. In addition, the child and the family might be eligible for disability allowance and cash-for-care benefits depending on the economic status of the family as well as the percentage on the medical report. While the diagnosis in itself is not important in securing these benefits, a diagnosis of mental retardation could secure longer years of education. Any kind of diagnosis becomes a permanent record accessible by the state authorities. This could possibly lead to stigmatization, which also led the parents to keep away from an official diagnosis as I have argued above. There have been some cases when the psychiatrist has either asked the family which diagnosis they prefer for example if they were considering sending their child to an integrated classroom.

In order to be eligible for services, the child needs to be evaluated by a medical committee. This committee conducts a disability assessment and prepares a report that contains a numerical amount of impairment. Based on this number, the family is eligible for disability compensation. This compensation could be of two types. Families with children under the age of eighteen who have been assessed to be fifty percent disabled are eligible for wages for home care as well as disability wages. However, this assistance is income based and only those families with low incomes are eligible for it.

Some of clinical sessions were devoted to coaching the family on how to score a higher disability level to be eligible for state services. At the hospital, where the “extreme cases” are seen, the diagnosis functions as currency, it brings diverse groups together and the higher impairment the child has, the more services he can receive. This is an important case of governing disability through this circuit. The reports of the medical board along with the percentages, levels of impairment circulate within the network. This has important consequences for defining personhood and citizenship. The diagnosis in and of itself is not important, it only makes sense within a general circuit of reports, special education and disability compensation.

According to one child psychiatrist working in private practice, “the children seen at the university hospitals (were) severe cases while private clinics often dealt with the grey zone: PDD-NOS, atypical autism etc.”. This observation in and of itself is very significant in understanding the trajectory of autism in Turkey, which is characterized by a deep polarization reflected in two different moral careers of the autism patient. Goffman argues that it is “career contingencies” that determine whether one ends up as a mental patient. Similarly, in the Turkish case, one can discern two divergent careers with totally different outcomes, one that leads to normalization and the other to “managed confinement”. The children I observed at the hospitals did indeed show severe symptoms, which were worsened by mental retardation and behavioral problems. While the ages ranged from eighteen months to twenty-one years, most of the patients were between five and ten years old. The majority had received none or very limited behavioral therapy, which had locked them into the severe condition. In the next section, I discuss therapy options that are available for these families.

Middle class parents, on the other hand, could consult the few private therapy centers without even getting a diagnosis. Children who enter the network of private medical care that includes psychiatrists, therapy centers and schools are often very young and they are “diagnosed” with atypical autism or communicational disorders or developmental disorder, anything but typical autism⁴⁰. Upon hearing this diagnosis, parents push for early intervention and intensive therapy. As children begin to respond to this intervention, this is used as further proof for their original classification in the category atypical autism⁴¹. I focus on the private clinics in the next Chapter.

The way children and families enter the mental health system has crucial consequences for the trajectory of the disease. There are two different economies of hope at work here. In the public system, inadequate services combined with the lack of incentives for normalization results in classifications of severe autism. In private networks, however, the hope of normalization combined with the absence of a diagnosis works in favor of the child and the family often resulting in mainstreaming by the time they start school.

⁴⁰ There is a similar dynamic in the USA where young children often receive a diagnosis of Pervasive Developmental Disorder- Not Otherwise Specified, which serves as a temporary diagnosis allowing the child to receive services until a final decision on diagnosis is made. According to a clinical psychologist working at a university hospital, more than half of the children on the spectrum between the ages zero and three seen at the child psychiatry clinic receive a diagnosis of atypical autism.

⁴¹ Based on a study conducted in Atlanta, Bhasin and Shendel (2007) report that higher social class (defined as higher maternal education and higher median family income) is associated with autism without mental retardation but not with autism with mental retardation. They argue that this could be explained by differential access to services. Children of lower socioeconomic status were possibly getting the diagnosis much later, once they begin school while children born into families with higher maternal education possibly began early intervention at younger ages hence mitigating other developmental problems such as cognitive impairment.

2.4. MANAGED CONFINEMENT

In the absence of an available network of therapies, the trajectory of a child looks very different when he enters the university hospital. The diagnostic session lasts at most twenty minutes and consists of an interview with the family and limited clinical observation. Follow-ups are almost always opportunities to talk about the side effects of medications and their effectiveness. Typically most of these children are on multiple medications to contain the behavioral problems or to facilitate language, communication and learning. The purpose is not to cure them or even to modify them but to mask the symptoms and to “manage” the disease. This has also been made possible by the introduction of the at-home-care allowance, which entitles a family member of the disabled person a regular income support. While this was a crucial development in extending the social rights of the disabled population, it also came at the expense of changing the disability categories and limiting eligibility. Individuals receiving income support has increased sharply in the recent years from 28,583 people in 2007 to 210, 320 people in 2009.

A typical day at the hospital clinic begins like this. The expert is presented with a large number of folders as he enters the room. The room is bare except for a desk, several chairs and a patient bed. It doesn't get much light and the room looks like it hasn't been renovated for a long time. Families with children crowd the hallways. They tell me they have been waiting since five in the morning. Since they can't make appointments over the phone, families have to show up very early in the morning so the physician can see them that day. As they receive “numbers”, the nurses retrieve their folders or for new

patients, they prepare new folders. As far as I could observe, health records were not digitized which created problems in sharing information across different departments.

There are often one or two families with children exhibiting severe behavioral problems like screaming or running around uncontrollably. These families get priority. As they are ushered in the room, the doctor glances at the folder and begins asking questions. Follow up sessions focus on changes in the child's condition and side effects of medications. Here is an excerpt from a typical encounter:

Psychiatrist: Are you giving him his medication?

Mother: Yes we are.

Psychiatrist: Does he go to school?

Mother: No he can't.

Psychiatrist: Does this (medicine) work?

Mother: No.

Psychiatrist: Let's prescribe another one. (Reviews his chart) We tried every medication. I don't know what else to give him. There is nothing I can do.

This daunting exchange is significant in exhibiting the limits of the profession in confronting autism and developmental disorders. The management of the disease can be frustrating at times and after a particularly difficult case, the neurologist simply admitted that "if I feel there is nothing I can do medically, I schedule the follow-up at a much later date". Depending upon the family, this could be three months or six months later.

Compare these two quotations from prominent child psychiatrists. They exhibit the despair of the expert in their inability to "heal" autism.

Like other colleagues who have worked with autistic children, I experienced unanticipated successes as well as disappointments. I fell into despair as I observed autistic children who

showed no improvements despite long years of intensive individual therapy. I was surprised and pleased to see the good results in cases that I met with occasionally and guided the mother. Based on my experiences, I have decided on the following conclusion: ...Those children who get the chance to be treated take advantage of the therapies at various degrees. ...In other words, each intensive therapy-education may not succeed because there may be insurmountable obstacles due to the child's nature (Yörükoğlu 1993: 4).

“There isn't much we can do”. This is what you often hear from us doctors and it probably doesn't cause anything other than strong emotions of despair and anger. More than the diagnosis of autism, it is our medical textbook knowledge that says there is no recovery that looms over the lives of the parents (Yazgan 2011).

These two quotations, almost twenty years apart, represent the main dilemma of the child psychiatrist faced with a child exhibiting symptoms of autism. In a context where psychiatric treatment is almost synonymous with the use of psychopharmaceuticals, the expert feels she is unable to offer any “real” treatment. In fact, as I have argued above the main strategy is still the use of pharmaceuticals not to treat but to contain and manage the disorder. While there is no proven medical treatment of autism, the use of Ritalin and Risperdal was very widespread. According to a neurologist, these medications are used for controlling repetitive behavior, aggression or extreme introversion and attention deficits. Most of the adolescents were also on anti-depressants, particularly on Lustral.

Despite inconclusive findings recorded in studies conducted during the early nineties, EEGs are still routinely ordered by psychiatrists for children exhibiting symptoms of developmental delays (Yörükoğlu 1993). While the EEG is not used for diagnostic purposes, it is used to “detect any abnormality in the brain”. The use of EEG in Turkey dates back to the sixties and it has been used to make a pre-emptive diagnosis before the symptoms of become visible (Taneli 2010). EEG is used to diagnose epilepsy when the child experiences seizures. However, in the Turkish context, EEG is a routine

part of the diagnostic session regardless of the existence of seizures. I would argue that this recourse to technology is a means to mask the incompetence of the medical profession to effectively intervene in the world of autism.

2.5. EDUCATIONAL DIAGNOSIS AND REHABILITATION SERVICES

The inability of the psychiatrist to help improve the condition of the children is compensated by a growing marketplace of therapies in the West. In Turkey, a family with no recourse to the private network of therapies is eligible to receive up to twelve hours of therapy per month after being evaluated at state funded centers called Rehberlik ve Araştırma Merkezi (Guidance and Research Center). Then they are referred to private rehabilitation centers called Özel Eğitim ve Rehabilitasyon Merkezi (Special Education and Rehabilitation Center). These centers have grown as a result of a law that was passed in 2005 in an effort to align disability services with European Union standards. This created an alternative economy of care. As soon as the government announced that it would subsidize some of the therapy expenses, there was an explosion in the number of these centers. According to a therapist while there were only a handful of them in Istanbul in early 2000, by 2009 this number had grown to around three hundred in Istanbul. I expected to find the formation of a new field of expertise as a result of the growing number of these centers. However, the kind of services that were offered were not specifically geared towards children on the spectrum. What they offered instead were mainly educational support for school aged children. Without the collaboration of middle class parents, the formation of such a field had failed.

As I mentioned in Chapter One, the origins of the Guidance and Research Centers date back to 1955 when Psikolojik Servis (Psychological Services), a center for the detection and diagnosis of children with special needs was established in Ankara. This was a sudden intervention in a field that had not received much consideration from state authorities and could best be explained as a consequence of the Turkish American rapprochement fueled by the Marshall Aid Plan of the 1950s. American educators including Elward Thompkins, John Rufi, Lester Beals and Otto Mathiasen conducted studies in Turkey while Turkish graduate students were sent to the United States to obtain degrees (Pişkin 2006). This created a visible American influence in the field of counseling and education (Stockton and Guneri 2011). However, the implementation of these policies and recommendations remained limited and the influence of Guidance and Research Centers were restricted to the few large cities. Their main focus was to screen, evaluate and provide guidance for primary school students including those who exhibit cognitive deficits. According to a research report, there were sixteen centers around Turkey in 1979. The report focuses on two major problems: inadequately trained staff and the cursory use of assessment tools (Çağlar 1979). The inability to develop indigenous scales or to improve and expand the use of screening tests could partially be explained by the lack of interest in Turkish academia towards education and pedagogy based on their claim that these fields were not “scientific” enough (Tan 2000: 40)⁴².

⁴² Following the recommendations of American experts, the Testing and Research Bureau was founded in 1953 in Turkey headed by George Prescott. The purpose of the bureau was to conduct scientific research in education, to identify, develop and diffuse methods of educational and psychological testing and assessment. The researchers translated and adopted multiple tests to be used in screening primary and secondary school students including IQ and Aptitude Tests. While this center showed potential in terms of the

Despite these problems, the influence of these centers continued to grow throughout the 1980s and 1990s. Two new regulations were passed in 1985 and 2001 to organize the role of GRCs in education. By 1998, the number of Guidance and Research Centers had grown to 93, by 2003 there were 127 centers and by 2012 there were 165 centers in Turkey (Akkök and Watts 2003; Günayer Şenel 1998; M.E.B. 2012). With the adoption of the new Regulation on Guidance and Research Centers in 2001, their function in the organization and provision of special education increased (Öz 2012). In addition to offering diagnostic and support services for students and children with special needs, they are also responsible for delivering guidance services in schools without guidance counselors as well as offering support to guidance services in schools (Akkök and Watts 2003). These centers are affiliated with the Ministry of National Education and are staffed by psychologists, special education teachers, guidance teachers and social service experts.

Guidance and Research Centers are effectively used as the primary mechanism of special needs assessment rather than providing broader psychological and guidance services (Doğan 1999). The primary reason for this could be the legal regulations on disability introduced in 2006. The Regulation on Special Education Services stipulates that children with special needs should be educated in the least restrictive environment ensuring maximum contact with their peers. In accordance with this principle, Guidance and Research Centers are designated as the primary center for the educational evaluation and placement of children with special needs. The same regulation also extended the state

creation of indigenous scales, it was closed down after a couple of years. For more information, see Tan 2000 .

subsidized twelve hours of therapy per month to all children with special needs regardless of social security status. In order to be eligible for these therapy services, the family needs to consult a Guidance and Research Center for the child to undergo an evaluation to receive an educational diagnosis at the end of which an individualized education program is created and the child is referred to a Special Education and Rehabilitation Center. To be eligible for state subsidized therapies at these centers, the family also needs to provide a medical report from the hospital, documenting 20percent impairment for each disability (this rate was initially 40 percent but was reduced to 20 percent with a new regulation adopted in 2010) and a diagnosis included in the educational support services program.

Any child can be referred to the Guidance and Research Center through the school, the pediatrician, the psychologist or the medical committee of the hospital. The family can also consult the centers on their own, no official referral is necessary. Evaluation, assessment and support services are free of charge regardless of the family's economic conditions. Children are referred to the center for multiple reasons including emotional problems, behavioral problems, attention deficits, cognitive impairments as well as for career guidance or violence in the family. A child with special needs is required to obtain what is called an "educational diagnosis" to be eligible for the state funded rehabilitation services. A medical diagnosis or a documentation of disability and impairment as assessed by the medical committee of a university or state hospital is not enough in terms of eligibility for these rehabilitation services and more significantly in

terms of placement in special education classes or integrated education⁴³. In fact, those who work at the Guidance and Research Centers have told me that “the medical report is not binding”⁴⁴ and they frequently use a different diagnosis than that provided by the hospital committee. This educational evaluation and diagnosis provided by these centers serve as a crucial rite de passage in the career of a child with special needs. For example, they may push the family to go back to the hospital to get a different diagnosis if they believe the real condition of the child is not reflected in the report.

Question: Do you evaluate children who show symptoms of autism but who do not have an official diagnosis?

Answer: Yes. We support them through the cognitive track (meaning the child probably has a diagnosis of mental retardation and they use this diagnosis to refer him to special education centers). We ask the family to get him evaluated for his autism. I often tell the family that I won't provide support for the child the following year unless they bring me a new report in order to force them to change the diagnosis.

One significant finding that was repeated both in the accounts of the psychiatrists who give the medical diagnosis and the experts at the Guidance and Research Centers who give the educational diagnosis was the differential treatment of families based on social and

⁴³ This situation is similar to the American case where students need to undergo an educational assessment and diagnosis to be eligible for special education. The diagnostic criteria for an educational assessment may differ from the DSM and the evaluation committee does not need to include a licensed clinical psychologist. (MacFarlane and Kanaya 2009)

⁴⁴ The original statement in Turkish was: *Hastanenin verdiği rapor bağlayıcı değil.*

economic capital. The special education expert differentiated between what she called the “conscious family”⁴⁵ and the others. This was a classification I often encountered in the field. According to this expert,

The doctors don’t want to give out autism diagnoses because the family encounters problems in school placement⁴⁶. We also don’t require an official autism diagnosis if the child has atypical autism, pervasive developmental disorder, if the family is supportive, if the family is “conscious”, if the child is benefiting from individualized education. If the family shows no awareness, we send them back to the hospital for a diagnosis.

An evaluation and assessment does not guarantee an autism diagnosis for all children on the spectrum. Only some are sent back to the hospital for a medical diagnosis. Families with the capital to negotiate can bypass the system and continue to receive services without a diagnosis.

Upon referral to the center, children are often assessed by the use of IQ or Aptitude tests. For those with mental retardation or autism, WISC-R and Leiter International Performance Scale are used. The purpose of the evaluation is to determine the extent to which the child needs special education. Having a documented disability is not sufficient to be placed in a special education class (Kargın 2007).

⁴⁵ The word used was *bilinçli*, which translates as conscious, aware, cognizant but the usage of the term in Turkey often masks a class bias. The conscious family has the social and economic capital to advocate for their child.

⁴⁶ A child with an autism diagnosis is at a disadvantage with respect to a child with dual diagnosis in terms of being placed in an integrated classroom. They can’t be placed in a partially integrated program; they either have to be fully mainstreamed or placed in a special education classroom for children with autism. I will discuss mainstreaming in more detail in the following chapter.

After the initial assessment, an Individualized Education Program is created which includes recommendations on specific educational modules to be followed in the Special Education and Rehabilitation Centers as well as information on the child's school placement. As I mentioned above, these centers have grown substantially as a result of legal regulations passed in 2005, which extended eligibility to all children regardless of their social security status. This regulation has created a booming market for private education services. As of 2012, there are 1,700 centers providing support services for 245,000 children. Of these children, 70,000 do not receive any formal education (OERD 2012). While the law requires individualized educational programs for children with special needs, in practice support services follow modules drafted by the Guidance and Research Centers based on the child's disability category. The module for mental retardation and for pervasive developmental disorders including autism do not show much difference and as a special education teacher working at a Special Education and Rehabilitation Center stated, in practice "there is even less difference in the way educational programs are used". Another expert working in special education argued that the therapy these children receive in state subsidized centers is not any different from what they would have received had they been institutionalized, that is therapy that is not individualized and fine tuned to meet the specific deficits of the child.

After the adoption of the legal regulation ensuring the least restrictive environment for children with special needs, children were not necessarily integrated within the formal education system. The services provided by these centers do not ensure integration in the form of mainstreaming. According to the Association of Special Education and Rehabilitation Centers, almost one out of three children receiving support

services are excluded from the educational system (OERD 2012). This is particularly true for lower class families who can't afford more than the twelve hours of therapy that is subsidized by the state.

This growing market of support services should be contextualized within the changing nature of the welfare state in Turkey. The conservative Justice and Development Party, which has been in power since 2002, has allied with the IMF to cut public spending (Tuğal 2007: 21). In order to do this, many services previously undertaken by state institutions have been outsourced to private companies particularly in the health sector. These services range from medical tests and diagnostics to educational support services (Grutjen 2007 : 62). According to a special education expert, while in the past, public school teachers may have undertaken such services as part of afterschool support programs.

2.6. MEDICINE, SCIENCE AND ALTERNATIVE PATHS TO HEALING

As argued in the first chapter, late Ottoman and early Republican Turkish thought was characterized by an unshakable faith in the power of science. According to Atabaki and Zürcher, it was what they called “scientism, a combination of positivism and biological materialism” that came to define the intellectual atmosphere of the time (2004: 4). The scientism of the time should be understood as part of the growing skepticism towards religion and all that was represented by the Islamic lifestyle of the past. In this increasingly secular system, science was to replace religion as exemplified by Atatürk's still quoted dictum “the only true spiritual guide in life is science” (Zürcher 2005 (1993),

289). Science was crucial in the imagination of a new nation. In contemporary Turkey, the polarization between science and superstition is one of the major defining factors of society. This dynamic plays itself out in the field of autism as well. While parents utilize biomedical therapies precisely because they deem those to be scientific, the medical establishment shuns these treatments as quackery.

Alternative therapies are another way in which these struggles over science can be traced. In Turkey, these therapies take the form of biomedical treatments, casein –free, gluten-free diets, chelation; but there are also other forms such as dolphin assisted therapy or neurofeedback. Experts in the field constantly warn parents against therapies that they deem unscientific and irrational. According to one psychiatrist,

They (therapists) present it (therapies) as a sublime experience, as something spiritual; they say there is a lot of progress. But progress takes time. This is how they present themselves and it is wrong.

Parents, on the other hand, prefer these therapies precisely because they believe that they are scientific. In fact, an analysis of an active listserv with over one thousand members dedicated to understanding the method of applied behavioral therapy yields an interesting result. Most of the messages share information on diets, allergies, hormones, chemicals and various treatments that parents have tried with their children. The conversations of these parents are informed by social fear surrounding pollution and contamination. However, unlike the American case, this is not simply environmental pollution. Parents are much less worried about the effects of vaccines for example, which

is a very contested issue in the West. The representation of autism in Turkey is informed by fears of over-westernization as well as a belief that Western science can cure autism. It is this contradiction associated with the interpretation of autism in Turkey that distinguishes it from other cases.

In the United States, biomedical treatments of autism have brought together parents, researchers and medical experts under the group Defeat Autism Now!, more commonly known as DAN!. Almost all of the parents that I interviewed mentioned the DAN! doctors. Some of the parents had attended a conference organized in Istanbul in 2008, which had featured Defeat Autism Now! Doctors. When I inquired about the doctors who used the DAN! protocol in Turkey, one mother answered:

They (the American doctors) are more scientific. They have been doing research for a longer time. These (the Turkish doctors) have just started. ... They don't run any tests. They have a typical diet. That's all you get from them.

While the therapies as advocated by the DAN! Protocol including detoxification, vitamins and diets are considered 'alternative' by the mainstream medical establishment, parents embrace it because of its scientific nature.

The exclusion of parents from the formation of the field of autism has rendered it totally different from what can be observed in the United States. As I will argue in the following chapter, parents are excluded from decision-making processes in the autism organizations, they do not have claims to expertise neither in therapy nor in advocacy. In fact, as one parent told me if an expert is also a parent of a child on the spectrum, this

casts a shadow of doubt on the capacity of the expert. When talking about a Turkish doctor who is in the DAN! Protocol, she replied, “his son is also autistic. So you think ‘what has he done for his own child that I should take my child to him’”.

Experts publish articles on the scientific method, science and therapy, science and autism trying to delineate the boundaries of a fuzzy field. Parents are told that not all biomedical treatments are scientific and not every therapy imported from the West is effective. One special education expert warns parents: “If you have a child exhibiting autistic symptoms, you should learn about the scientific method. Otherwise, it won’t be easy for you to find the truth for your child. Don’t forget that without the light of science, it is not possible to make progress in any area” (Kırcaali İftar 2008). Then she goes on to explain how the theory that the secretin hormone has been beneficial in the treatment of autism has been refuted by science. According to Kırcaali-İftar, this theory had no plausibility in the first place because it was based on parents’ testimonials and not the scientific method. The dismissal of the agency of the family is integral to the organization of expert knowledge in Turkey.

In an effort to claim sole jurisdiction on the field of autism, psychiatrists publish and give talks on the true boundaries of autism therapies. They situate themselves as having a direct access to the scientific method while the others are shunned because of their proximity to the market. These struggles become even more prominent in the field of autism as they are integrated into what Novas calls the “political economy of hope”. One prominent psychiatrist begins his essay on “marginal theories in autism” by admitting that “we, the doctors are at fault”. He goes on to explain how doctors have been pushing families to alternative treatments because of their pessimism and their insistence

on labeling autism as untreatable. In his treatise, Yazgan describes the problems within the medical field:

In our efforts not to give unjustifiable hope to parents, to be honest, to transmit the only interpretation of truth (partial recovery is not cure) to the parents, we have led them into unnecessary pessimism and to marginal alternatives that I hesitate to even call alternative therapies, with our own hands. ... We are at fault because we caused pessimism and because we couldn't control the field. (Yazgan 2011)

Almost all of these articles devote sections to an explanation of the scientific method; the difference between science and propaganda, between science and pseudoscience⁴⁷. The parents are warned of the possible side effects that may arise from the use of techniques such as high-pressure oxygen therapy. While the medical experts are involved in boundary work, parents try to push those boundaries and blur the definition of “scientific treatment”.

The underlying effort in these discussions is an effort to distinguish faith from science. This brings us back to the polarization introduced earlier, between West and East, between science and religion (faith), between rational thought and superstition. The medical establishment's claim to jurisdiction is based on the survival of this polarization. Interestingly, they are surprisingly silent on the issue of spiritual healing which is probably more widespread than biomedical treatments. This is the unspoken side of therapies. One therapist told me that most of the children she works with wear protective amulets or charms. In fact, the parents that I met especially at the university

⁴⁷ See also Semerci's article which was also published on Tohum's website.

hospitals had already taken their children to see the religious healers. As I mentioned in the previous chapters, the scope of this research is limited to the urban centers and “Western” techniques of intervention. The pluralism of the health care environment has been well documented in other contexts⁴⁸. While this multiplicity of therapeutic practices holds true for Turkey, scholarly work in this area remains very limited. This could partially be explained by the opposition toward religious and traditional forms of healing particularly among the medical professionals. According to Dole, this is not simply a professional competition over patients or a medical critique. Instead, interpreted within the broader Turkish modernization project, “the larger project of marginalizing particular religious and social practices so that they can be supplanted in the name of a national image befitting a properly modern nation” (2006: 47).

People consult traditional healers with regards to a variety of problems that include infertility, impotence, fainting and psychiatric problems (Strasser 2000). Recent literature has documented the wide prevalence of the use of traditional healing methods. While the rates found in the studies range from 26.9 percent to 82 percent, consulting traditional healers and shrines is an important help seeking mechanism in the Turkish population (Edirne et al. 2010; Özden et al. 1997; Uğuz, Karababa and Aşkın 2007; Yaşan and Gürgen 2004). This is particularly true for psychiatric diseases (Güleç et al. 2006; Güner Küçükkaya and Ünal 2012; Kırkpınar 1992). According to Dole, the field of traditional healing in Turkey is organized around Islamic principles and people often consult healers for health issues not defined as treatable within the biomedical paradigm

⁴⁸ For general overviews see Baer 2005; Chrisman and Kleinman 1983; Singer and Baer 1995. (Chrisman and Kleinman 1983; Singer and Baer 1995) For case studies, see Baer 2001; Brodwin 1996; Broom 2009; Lock 1984. (Brodwin 1996; Broom 2009; Lock 1984)

(Dole 2008). This is particularly significant for the case of autism as even the medical experts have recognized their inability to change the course of the disease.

Even though help seeking behavior in alternative treatments is spread widely among rural and urban areas and among all socioeconomic classes, this pluralism is not recognized by medical practitioners. The reactions range from dismissal of Islamic therapies to active antagonism. Unlike biomedical treatments, Islamic healing can exist side by side with the treatment program of the medical establishment/therapy/ special education alliance. As long as it does not infringe on the professional jurisdiction of the medical field, Islamic healing is rendered invisible. However, Dole argues that this relationship is deeply political. Basing his discussion on the intimate relationship between the Turkish modernization project and the medical field, he argues that “the religious forms of healing have emerged as targets of widespread antagonism among those who perceive recent Islamic electoral success as a threat to Turkey’s democracy” (Dole 2004).

2.7. AUTISM AND THE POLITICS OF MOTHERHOOD

Historically autism has been almost synonymous with mother blaming. In locating the causes of autism, Bruno Bettelheim, among others, has blamed the family particularly the mother of withholding attention, love and care from the children, what has come to be known as the “refrigerator mother” theory. This psychogenic theory, which was popular in the 1950s and 1960s, has been dismissed in favor of a biomedical explanation as a result of parent advocacy. However, a discourse of blame that employs the trope of the mother as the educator was still widespread in Turkey. In fact, in explaining autism to the

families, most of the experts emphasized that “wrong mothering” could be preventing the normal development of the children.

This new narrative that emphasizes the role of the parent, especially the mother in unleashing the hidden potential of the child is reminiscent of earlier theories. In the Turkish context, this narrative is also embedded within a framework of increasing concerns over women’s entry into the workforce as well as the dissolution of the extended family network. For example, while explaining the disorder to a family, one expert said:

I can’t say this child’s condition will turn into autism. (His communicational problems) could be caused by a lack of stimulation. No more TV, no more visual media and then we’ll see what happens. Television is forbidden. Just like it’s forbidden to smoke for someone who has cancer ... You need to play with him, make eye contact, call his name, make him respond, play ball. Just be a mother.

Controlling television exposure was probably the most common prescription that I encountered during my fieldwork. Television viewing was symptomatic of all that was lost from a romanticized past when mothers stayed at home and the children grew in large extended family networks. According to one mother,

Actually, (autism) is an indication for us. It is telling us to live like our grandmothers, our grandfathers. We have been eating processed food, living in chemicals. It is a sign for us to go back to life as it were.

Mothers have also accepted their role in this narrative. As one mother put it,

Life was very difficult with twins and we have nobody here, in the city. No other family members. I had to sit them down in front of the television to get them to do anything. ... After getting the diagnosis, I was told by the (development) specialist to limit the amount of time they watched television. Ahmet used to space out while sitting in front of the television. I would put Baby TV on, thinking they would benefit from it, but it was so harmful.

The mothers that I interviewed blamed themselves for not stimulating their children enough, for keeping their children busy with television, for leaving their kids with nannies, in general what they referred to as “ineffective mothering”. It is very interesting to observe that television had taken the place of vaccines as possible triggers of autism in Turkish culture. Even though parents were actively researching biomedical remedies for autism, there was no visible discussion of vaccines. This could also be explained by the growing skepticism towards the West.

A closer look at the field of mental health reveals that controversies in other fields are also informed by the specific neoliberal anxieties of Turkish society. Particularly, in the field of Attention Deficit and Hyperactivity Disorder (ADHD), there have been several public debates. Most often, these debates focus on the over-medicalization of children leading some to question the validity of the diagnostic criteria. The cultural essence of the debate may seem similar to what has taken place in the U.S. in the 1970s as exemplified by two main publications, which have questioned the essence of the disorder (Conrad 1976; Schrag and Divovsky 1975). However, these debates in the Turkish context are also informed by a growing resentment toward the

dominance of American influence in psychiatric care and particularly in the extending use of psycho-pharmaceuticals⁴⁹.

According to recent epidemiological studies, the prevalence of ADHD in Turkey is 8.6%, somewhat lower than that found in the United States (Gul et al. 2010). However, a more significant finding has been the higher rates of ADHD found in the more urbanized Western parts of Turkey compared to the eastern parts (Erol et al. 2008). The rural urban divide in terms of access to mental health care as well as disparities in diagnoses should be seriously considered in evaluating mental health outcomes for children. The families of children with ADHD are not as visible as those families whose children present symptoms of autism. Even though the prevalence of ADHD in Turkey is higher compared to autism, the families have been reluctant to organize to demand improved specialized services for their children.

Schizophrenia provides another interesting comparative case. The families of individuals with schizophrenia have been the first group to form an association. Mental health care in this area has focused on pharmaceutical care at the hospital (Yazıcı and Yanık 2007). The foundation of the Friends of Schizophrenia Association was important in establishing the visibility of mental illness and fighting against stigma. What is significant about this formation was that it almost functioned as a “day hospital” for those suffering from schizophrenia (Kesal 2005). This was also important in enabling the patients to take an active role in organizing for their rights.

⁴⁹ See for example a series of articles written by a mainstream journalist in 2011 against the diagnostic criteria of ADHD and the resulting public debate which got an extended media coverage. For a list of articles see: <http://dikkatsiz.blogspot.com>

2.8. CONCLUDING REMARKS

In her study of autism in India, Daley contends that lower class children are less likely to receive a diagnosis of autism because their symptoms would get lost among the overcrowded state hospitals (2003). This sounds like a reasonable argument particularly in a non-Western context. What is so puzzling about the Turkish case is that lower class children would be more likely to get the diagnosis because they are more likely to receive a diagnosis if they see a specialist at a university hospital. The care of children with severe developmental delays presents itself almost as a continuation of the institutionalization paradigm. In the absence of a well-established policy of normalization and parental activism, the main strategy adopted is that of managed confinement, not in institutions but in the family.

Chapter 3

Private Care and The Marketplace of Therapies

I mostly see children with NOS (*Not Otherwise Specified*). The reason I believe is this. Pure autism is rare. PDD-NOS (*Pervasive Developmental Disorder- Not Otherwise Specified*) is more common. Also, with increasing awareness, we began to see more children under the age of three. For the family of a child under 3 to say 'there is something wrong with my child', (the family) has to be alert and conscious, with a high level of education, a family that cares about their child's development. Not a family that simply thinks 'we brought this child into the world, he will grow up on his own'. These families have a certain mental capacity. They pass it on to their children. I believe this. (These children) have very good qualities, they also have communicational problems not specifiable in other ways.

This was how a therapist described the profile of the children and therapists she met at her private practice. Indeed, the children at these private clinics did not resemble those I met at the large hospitals. Unlike the inconsolable children with tantrums at the hospital, these waited patiently at the luminous and sterile waiting rooms often choosing not to engage with multiple developmental toys scattered around the room. This difference presented an interesting puzzle. When I asked the therapist about my observation, she simply argued that she met milder cases at her clinic, but when probed further the structures leading to this polarization became transparent.

In this chapter, I will show that the particular class structure, professional struggles and the changes in the welfare state have resulted in a unique configuration of the system of diagnosis and therapies of autism in Turkey. In the absence of

deinstitutionalization, middle class parents have forged an alliance with psychologists and educators around autism as a “disorder without a diagnosis”. Unlike the American case, the diagnosis does not provide the children with better services or state support or disability rights. Hence, the middle class parents opt for the private market and consequently do not need a label or diagnosis for their children. The psychologists and educators, on the other hand, do not need a diagnosis because they want to avoid appearing to encroach on the jurisdiction of psychiatrists especially in a field characterized by intense professional struggles. They also avoid the label because they want to maximize flexibility in admission policies. As a result, there is a jurisdictional settlement between psychiatry and psychology based on a division of clientele where the educators and psychologists focus on catering to the need of middle class parents to mainstream their children.

Families who can afford private care may never take their children to the university hospital for a diagnosis. They see specialists in their private practice⁵⁰. They are then referred to Psychological Counseling Centers, which cater to a wide range of problems including Attention Deficit and Hyperactivity Disorder, emotional problems, test anxiety, bedwetting, toddler tantrums, sibling rivalry, speech problems, learning disability and autism. While the therapeutic methods change according to the training background of the experts at these centers, the most common methods are cognitive play

⁵⁰ Even if they do end up taking their children to the child psychiatrist or the pediatric neurologist at the hospital, they may still avoid the label particularly if they are a family that the doctors interpret as “being in charge of the situation”. This is also true for the educational diagnosis given at the Special Education and Guidance Centers.

therapy, psychodynamic therapy, behavioral therapy and relaxation methods. Some also apply methods inspired by psychoanalytical techniques particularly influenced by the theories of Donald Winnicott and Anna Freud. In this chapter, I will focus on this alternative career to that outlined in the previous chapter. I start the chapter with a brief discussion of occupational struggles in the field of therapies and the particularly precarious position of the psychologists and the Psychological Counseling Centers. Next, I will analyze the moral career of a child with a higher socioeconomic background who is referred to these centers. In the second part of this chapter, I will focus on the promotion of education as the cure of autism. This will include a detailed analysis of educational techniques used for autism as applied in an autism school. I will discuss the implication of these methods for the development of a new understanding of personhood and ways of working on oneself. I will finish the chapter with an analysis of moral images of autism employed by parents and experts.

3.1. STRUGGLES IN THE FIELD OF THERAPIES

In the absence of any national mental health policy, the field of mental health care in Turkey remains porous and open to invasion from neighboring professions. As a result of the changing nature of the welfare state, the health care system is increasingly being privatized which is aggravating the competition among the various professions. Particularly in the 1990s, there has been a significant growth of private therapy centers especially in urban areas. This resulted in the pluralization of the mental health care field

as psychologists, educators and psychological counselors flocked into the field introducing various forms of psychotherapy and intensified the competition.

As I argued in the previous chapters, historically psychiatrists have acted as gatekeepers for access to mental health care. For a long time, the psychiatrists have resisted legal attempts for the recognition of psychology as a profession (Batur 2006). The pluralization of mental health care options was interpreted as an incursion in their territory. In order to maintain their professional jurisdiction, in 2010 the Psychiatric Association of Turkey put pressure on the Ministry of Health to take action against the Psychological Counseling Centers where psychologists and counselors work with no supervision from psychiatrists. This move was an extension of the psychiatrists' increasingly medicalized interpretation of mental health care. In a report published in the Bulletin of the Psychiatric Association detailing the task areas of various professions, psychologists, clinical psychologists and counselors are excluded from acting independently in diagnosis and treatment based on their lack of clinical experience and insufficient medical knowledge (Türkiye Psikiyatri Derneği 2010). The most significant consequence of this move has been the increasing involvement of psychiatrists at these centers.

While psychologists have allied with psychological counselors in the formation of this alternative network of private care, these two professions are engaged in a struggle over clientele. This struggle has become more evident as the Ministry of Health moved to draft a new bill in 2011, which identifies who can legally practice mental health care and

charts the task areas of mental health personnel ⁵¹. According to this bill, “the clinical psychologist who is a member of the health care personnel has an undergraduate degree in Psychology or Psychological Counseling and Guidance and a Masters degree in clinical psychology or a Doctorate degree in clinical psychology in addition to the Masters Degree”. The Turkish Psychological Association recommended that graduates of Psychological Counseling and Guidance not be included in this definition, which caused uproar from the psychological counselors. This recommendation was not taken into consideration as the new bill came into effect. However, this controversy was significant in understanding the changing nature of the field of therapies in Turkey.

As I argued in Chapter One, historically mental retardation has been the jurisdiction of psychologists and educators in Turkey. The detection and treatment of cognitive disabilities was confined mostly to schools and a limited number of residential facilities. This was also reflected in the academic organization of the professional fields. Initially, the psychology department was included under the Institute of Pedagogy and the Faculty of Education. During these early years of the Republic, the purpose of these fields were to “engage in problems of education” (Batur 2006). After the 1960s, as the number of Psychology Departments grew and were integrated under Arts and Sciences, there arose a new division of labor whereby the departments of Psychological Counseling and Guidance, which were included under the Schools of Education assumed a more active role in issues of education (Kağıtçıbaşı 1994). The history and the current state of the counseling profession is deeply connected to the history of education and pedagogy in Turkey. In fact, it is this relationship that the psychologists used in their efforts to exclude

⁵¹ Law No. 2/889 March 21, 2011

the counselors from the field of mental health care. According to the psychologists, counselors are effectively “teachers” who work as guidance counselors at schools and hence can’t be included as part of the mental health care system. Turkish Psychological Counseling and Guidance Association, however, countered this claim and succeeded in getting included in the new bill. In their statement, the association argued that “being a part of the Faculty of Education is simply an administrative arrangement and does not mean that counselors can only work as teachers” (Türk Psikolojik Danışma ve Rehberlik Derneği 2012).

While there are currently forty universities offering undergraduate degrees in Psychological Counseling and Guidance, the field is still in the process of institutionalizing its boundaries (Türk Psikolojik Danışma ve Rehberlik Derneği 2012). In addition to providing counseling services at schools, counselors are also employed by the state-run Guidance and Research Centers, which provide counseling and educational testing to students with and without special needs. Unlike its American counterpart, counseling in Turkey has remained within the educational system and could not branch out to community mental health care or to private practice to the same extent (Stockton and Guneri 2011). As the significance of the Guidance and Research Centers increased particularly through their key role in acting as gatekeepers for which children can receive state sponsored rehabilitation services, the jurisdictional struggle between the various occupations claiming to serve the now growing pool of families with children of special needs intensified. More importantly, some of the counselors who had been working in the field of special needs moved to private therapy centers. Historically the counselors had been more involved in the rehabilitation of various forms of impairments especially

because such work began at schools. This care was limited to state institutions and was understood to be “education”. With the creation of new centers for therapy, this authority began to be challenged by the psychologists who claim to be sole authority on the therapeutic care of children with special needs.

A major problem that counselors have faced is what is referred to as *açıktan atama* or the appointment of unqualified personnel by the Ministry of National Education to counseling posts including schools and *Guidance and Research Centers*. Typically these are graduates of education programs or social sciences and they receive little to no training before appointment (Pişkin 2006). This is a strategy often employed by the state to tackle the problem of insufficient personnel. One consequence of this policy has been the lack of institutionalization in the field of Psychological Counseling and Guidance. In addition to these problems, graduates of this program are often excluded from professional activities organized by psychology associations. The primary mechanism of control is through the exclusion of counselors from trainings, particularly training in the administration of psychological testing. Since the Turkish Psychological Association has monopolized the trainings in some crucial tests including the Wechsler Intelligence Scale for Children (WISC-R), this has important consequences for guidance counselors’ claims to authority in the field of mental health. So far, no jurisdictional settlement has been reached (Abbott 1988). The psychologists do not want to share the jurisdiction of special education and are trying to push the counselors out of the field into educational counseling in mainstream schools. However, given the vast shortage of professionals in the field of special education,

3.2. PRIVATE CARE AND DISASSEMBLING THE SPECTRUM

While it is not possible to discuss in detail the historical contingencies that have resulted in the emergence of the idea of the spectrum in the United States, I will provide a brief summary in order to provide a comparative lens through which we can evaluate the Turkish experience. As Eyal et. al. argue, as the institutional matrix of custody began to disintegrate with deinstitutionalization, autism was transformed from a rare disease to a large spectrum encompassing a wide range of developmental disabilities. Parental activism was a key part of this process. A significant element in the extension of autism into a large spectrum in the United States involved the blurring of the boundary between the expert and the parents as well as between mainstream and alternative medicines. As they argue, “(f)uzzy zones, like the one between established and alternative medicine, surround the space of autism therapies on all sides, each in its own way blurring the edges of the diagnostic category of autism and extending the spectrum to new populations of children” (391). In this dynamic, they emphasize the role of autism therapies placed between medicine and special education, between academia and the market and “open to incursions from all these other fields”. The crucial point, however, is that they have been able to reap the profits of this strategic expansion through striking a coalition with the parents. This has been crucial in the formation of an idea of the spectrum where autism functions as an umbrella term including multiple symptoms, different impairments and more significantly various cognitive capacities. According to Eyal et. al., the most crucial dynamic was possibly the re-organization of the relationship between autism and mental retardation. As autism began to be understood to be co-

morbid with mental retardation, the two conditions became interchangeable eventually resulting in a diagnostic substitution powered by the parental interests (259).

As I have argued in the previous chapters, two different forces in Turkey dominate the field of autism: the psychiatrists and the special education expert/psychologist. Curiously absent from this picture are the parents. While I will discuss the role of parent activism in the following chapter, suffice it to say that a different form of alliance between the parents and the therapists based on the negation of an autism diagnosis has resulted in the disassembling of the autism spectrum in the Turkish case. The therapists, working in private practice at a Psychological Counseling Center, who often had degrees in psychology or psychological counseling and guidance were keen to steer the families away from an autism diagnosis precisely because there was not much to be gained from an autism diagnosis particularly for a middle class family. One therapist explained her position to me:

I don't need the diagnosis because I know what I need to do. Obviously there are some problems with the child. We can take care of him without a diagnosis. We say he has impairments in these areas, he doesn't make eye contact, he has developmental problems, problems with gross motor and fine motor skills. This is how we label him. We don't talk about a diagnosis. ... Of course we prefer (families) who come to us with a list of their child's problem areas instead of asking whether (their child) has autism. I mean when we tell the family to get their child assessed, get a label, the family is even more confused. It is more reasonable to guide the family without a diagnosis.

This provides an interesting contrast to other cases. Lorna Wing, a parent and an autism researcher working in Britain is similarly wary of obsessing over the diagnosis but for different reasons:

The diagnostic labels don't mean a damn thing-just use them to get the person the services they need. What makes me mad is that some people get so wound up about a specific diagnostic label. (Feinstein 2010: 295)

The crucial difference between the two cases lies in the structure of the welfare state. An autism diagnosis in Turkey only provides state subsidized twelve hours of therapy per month (eight hours for individual and four hours for group therapy) (M.E.B. 2009)⁵².

This therapy takes place at Special Education and Rehabilitation Centers, which are not well equipped to provide the specific therapeutic conditions necessary for children on the spectrum. They work with centrally mandated modules for each special needs category.

While these modules do incorporate some behavioral interventions, they are predominantly designed to function as educational support systems for students since this was the original purpose of these centers. Additionally, these centers are often staffed by professionals with limited training and experience in the field. According to a recent study, parents are unsatisfied with the limited hours of therapy their children receive as well as the lack of individual treatment possibilities at these centers (Yıkımlı and Özbey 2009). While the state subsidizes 8 hours of individual therapy per month, children may

⁵² As I mentioned in the previous chapter, all children with special needs obtain this right as long as they can obtain a twenty percent disability report from the Medical Committee of the State Hospital. In this sense, an autism diagnosis is no different from mental retardation or learning disability.

be receiving group therapy instead of individual therapy due to the inadequate number of personnel. Hence, the provisions gained from an autism diagnosis remain ineffective and insufficient. For middle class families, these services could be found in the private market.

What is in fact taking place is a new alliance gathering around a “disorder without a name”. Middle class families are distancing themselves from the diagnosis both because the services to be gained with a diagnosis are negligible but also because of the stigma attached to the diagnosis. These parents are working within the normalization paradigm and they are aware of the problems an autism diagnosis may cause if they want to eventually integrate their children in mainstream education. This newly forming network wants to disassociate itself from all that is reminiscent of older kinds of mental disease particularly mental retardation and the only way to do this is by disassembling the spectrum. As opposed to the “conscious family” who does not need an autism diagnosis to seek care for their child, the other families need to be disciplined through labeling since they lack the resources to self-govern. Here is how one therapist describes the “other” families, those who have autism:

If you look at the bell curve, pure autism is very rare. The families of children with autism are those who don't compare (their children to others), who don't care about child development, who believe 'just as he is born, he will grow up', who see their children as quiet, introvert. I don't want to say they have given up on their children, but...In any case, these families do not belong to a middle to higher socio-cultural class. They are not inclined to notice the differences, to research and improve themselves.

This presents an interesting contrast with the American case. When autism was initially identified by Kanner in 1943, he emphasized that the children that he observed

came from “highly intelligent” families who were well educated and belonging to a higher socio-economic status (1943). In fact, up until the 1970s, autism was identified as a middle class disorder as opposed to mental retardation, which was widespread among the lower classes. There were a number of studies investigating the relationship between class, race and autism, which emphasized that the “class bias” could be explained by referral and diagnosis practices (Schopler, Andrews and Strupp 1979; Wing 1980). After the 1980s, with the rise of diagnoses, researchers began to argue that there was no discernible relationship between socioeconomic status and autism. As Eyal et al. argue, the crucial dynamic in this transformation has been the extension of diagnosis and early intervention services to all social classes in the aftermath of deinstitutionalization. This was possible as a result of collaboration between parents and therapists.

In Turkey, however, the field is characterized by a jurisdictional division whereby psychiatrists care for clients who can't afford private care, taking on mental hygiene for the state. Psychologists, on the other hand, provide care for middle class clientele by defining the problem as an educational rather than medical problem⁵³. The parents and the therapists ally to keep the middle class children away from a diagnosis particularly because those diagnoses are associated with university/state hospitals, state rehabilitation centers, all that is associated with an older understanding of disease, the mentally retarded children who are hidden away in the back rooms or who are known as the

⁵³ It is important to note that these divergent careers could not simply be explained by the jurisdictional settlement between psychiatrists and psychologists. In other contexts such as the United States and Britain, psychologists shoulder the majority of the therapy work defining it within the psychological/educational paradigm. The defining factor is the lack of welfare provisions and the choice of middle class parents to opt out of the autism network.

“village madman” as one psychiatrist put it⁵⁴. What is taking place in the Turkish case is reminiscent of the American field before deinstitutionalization. Here we have parents and experts trying to disassemble the spectrum so that the two moral careers do not converge. Pure autism, the extreme cases of autism with behavioral problems and mental retardation are relegated to the university/state hospitals while middle class parents make alliances with therapists and experts working in private practice try to do away with the diagnosis altogether. Middle class parents are more likely to notice the problems and bring their kids in to a private care center. There were, in fact children as young as 18 months receiving therapy. Younger children who began intervention at a young age exhibit less of the behavioral problems, the stems, and repetitive behavior since they began to work on them early on. Early intensive services sometimes could make the diagnosis less relevant. The therapists are, then interested in children who “have a lot of untapped potential” and through early intervention “learn how to use that potential”. When they start school they are simply “weird kids” with some “fixations and attention deficit disorders”.

⁵⁴ In extreme cases, they are institutionalized in asylum like hospitals. According to one of my informants, there is a closed section at Bakırköy Hospital, the largest mental hospital in Istanbul which houses institutionalized patients where if screened 90 percent of the patients would possibly get an autism diagnosis.

3.3. MEANINGS OF EDUCATION

In the Autism Matrix, Eyal et al. argue that the spread of therapies such as Applied Behavioral Therapy (ABA) has been possible because parents and therapist formed an alternative network of expertise and challenged the dominant psychiatric establishment. This, they argue has been possible as a result of the space that opened up after deinstitutionalization. In the absence of any real history of deinstitutionalization, the Turkish case provides a unique case to study the development of the field of therapies⁵⁵. The field of therapies for autism spectrum disorders is a battlefield for parents and individuals on the spectrum. There are multiple therapies and each works with different techniques and tools but also within different metaphors of the child, with a different conceptualization of personhood. Hence, the field is extremely politicized. These therapies are distinct from special education even though there is often some crossover between the two fields. What is distinctive in the Turkish case, however is that there is almost no mention of the word therapy. Instead, experts refer to themselves as educators, parents adopt techniques of education in dealing with autism and organizations advocate that “the only cure of autism is education”. The field of therapies has been absorbed into the field of education.

When parents and experts talk about the treatment of autism, they rarely mention therapies. Most of the focus is on children’s education or *eğitim* as it is called in Turkish.

⁵⁵ Therapy is translated as *tedavi* in Turkish and it also carries the meaning of *cure*. This could also be part of the reason why the term education instead of therapy is adopted in Turkey. The object of treatment is not cure or recovery but normalization as defined by the possibility of the child to study in an integrated classroom

Even though *eğitim* refers to formal education, it is often evaluated in relation to the word *terbiye*, which means “moral education”. It is this double meaning that is so significant for understanding the field of autism intervention in Turkey. The objective of therapy is to tame the undesirable behaviors while instilling social skills in the individual to make him an autonomous member of society. This is even more visible in the case of the autism school discussed in the following section.

3.4. THE AUTISM SCHOOL

As part of my fieldwork, I conducted observations and interviews at an autism school, which was based on the use of Applied Behavioral Analysis (ABA), possibly the most well-known method in the field of autism. This was a private, elite school founded by the TOHUM Foundation in 2006 and in the autism circles it had a reputation of being the best school, and according to some parents the only school that can effectively work with children on the spectrum. As of 2011, 93 students between the ages of three to fifteen were enrolled in the Autism School. Of these students, only 22 attended school full time, which includes at least forty hours of individualized therapy per week. The remaining 71 students receive rehabilitation services of two hours a day, two to five days a week. Those who attend the school full time receive at least forty hours of individualized education per week. The cost of attending the school was considerably higher compared to the other autism schools. In 2011, 45 students received fully subsidized education financed by donations. In Turkey, there is no insurance system that could cover these educational expenses. However, those children who have been evaluated at the Guidance

and Research Centers are eligible to receive twelve hours of therapy per month that is subsidized by the state. Hence, part of the educational costs of some of the students enrolled in the rehabilitation services at the school was financed by the state. However, TOHUM remains an elite institution with fees that only upper-middle class families can afford.

TOHUM Autism Foundation was established in 2003 as a non-profit organization. The objective of the foundation is early diagnosis and education of children with autism and developmental problems. Their special education program is developed by Princeton Child Development Institute (PCDI) in the USA. According to one of the founders of the organization, they decided on PCDI after visiting and observing multiple other schools that provide special education to children on the spectrum in the United States. They picked PCDI because “it is the best institution to transmit its know-how and it has the highest percentage of children who end up in mainstream education”. The prospect of mainstreaming was in fact a crucial factor both for parents and for the staff at the school. This was one of the major objectives of the school.

PCDI is an institution that is involved in the dissemination of Applied Behavioral Analysis by sharing model programs in intervention with other professionals in the field. For this purpose, PCDI offers pre-doctoral and post-doctoral residencies for teachers with graduate training in behavior analysis. The program includes training in behavioral therapy, autism and hands-on experience in the classroom. These residents include those who come to the institute from outside of the United States with the intent to develop similar systems in their own countries (McClannahan and Krantz 2008). The director of the TOHUM School had also received training as a post-graduate fellow at PCDI. One of

issues emphasized by the staff was how strict they have been in replicating the PCDI system. According to one of the founders: “whatever the system is in the USA, we have the identical system; we do not tolerate any deviations.” This strict adherence to the behavioral method developed at Princeton also draws criticisms from the autism community. One special education expert I interviewed was hesitant about the universal applicability of ABA and was critical of TOHUM’s reluctance to recognize the effectiveness of other forms of therapies for some children on the spectrum.

There are long waiting lists to get into the school and a pre-admission interview is required from the students and the parents. While this interview is designed to assess the student’s skills and identify the areas in which she may be exhibiting delays and impairments, it also serves as a pre-selection mechanism. When asked about the importance of diagnosis in getting accepted to the program, an administrative at the school mentioned that they welcome all children with an autism diagnosis. I was told “the crucial issue is fitting the group; even if they exhibit symptoms of mental retardation what matters is being a good fit”. Being a “good fit” is generally understood as children who show potential for mainstreaming possibly excluding some children with extreme behavioral problems. This strategy was also reflected in the school’s emphasis on early childhood education and their efforts to include younger children within the school program.

The children that I observed at the school had relatively mild behavioral problems. Even though the school officials told me that every child on the spectrum has an equal chance of getting in the school provided that he wins the lottery, others have told me that the interview process is very selective and they tend to accept children who don’t

exhibit extreme behavioral problems, who show the potential for eventually being integrated into mainstream education. In fact, the profile of children at the school was radically different from what I had observed at the university hospitals. This brings us back to the moral career of the child. Most of the children got admitted with a diagnosis of pervasive developmental disorder and as a result of intensive therapy, they get locked into this trajectory. Some of them have already been mainstreamed and possibly lost the diagnosis altogether. The teachers often mention these students as success stories.

Another fundamental issue was the assessment of parents. It was imperative to identify “cooperative parents”. As the coordinator put it, “it is important that the parents fit the program because this is not a place where you send the kids and then forget about them”. In fact, during my fieldwork, some teachers mentioned a student who lost his scholarship because the parents did not cooperate. “They did not do what we asked them to do; they did not bring his reports. We could not discipline this family. The student was already aggressive and he became more agitated.” After this pre-selection, admission is done through a lottery system. I met families who had been on the waiting list for years trying to secure a spot for their children at the school. The TOHUM school is viewed as an escape from the harsh realities of the autism world and parents carry high hopes of eventually “integrating their child to society” after attending the behavioral program at the school.

The emphasis on integration is also reflected in the PCDI program. The goals of the Princeton approach are “to teach spontaneous and functional communication skills, develop self-initiated learning skills, and minimize disruptive behaviors to improve the chances that a child will be able to function, to as great an extent as possible, in the

mainstream” (Siegel 2003: 411). Both TOHUM and PCDI emphasize that their students transition to inclusive programs after receiving training in these schools. PCDI boasts of a 50 percent success, which is often referenced in the narratives of TOHUM. The meaning of integration may have different meanings in different contexts, however. In Turkey, the shift to integrated education implies that a student needs to adapt to mainstream schools through various behavioral interventions rather than the schools transforming their approaches and adapting themselves to a more diverse student population (Tohum Otizm Vakfı 2011). Inclusive education, on the other hand, could mean a more radical transformation of educational techniques and approaches that would enable the accommodation of students with special needs. In order to prepare for mainstream education, a student would need to “gain control over his behaviors” and should have internalized some skills, particularly communication skills. The program of the school reflects these two main targets. The majority of the effort is concentrated on behavior management while the academic curriculum focuses on the development of communicational skills through the use of particular technologies. In the rest of this section I will provide a discussion of these two targets based on my fieldwork

3.4.1. MANAGEMENT OF BEHAVIOR

Applied Behavioral Analysis is based on behavioral psychology and aims to teach skills through a reward system, what is referred to as the “token economy” (Matson and Boisjoli 2009). Behavioral modification is structured around a system of value, each behavior has a value in tokens. The child is asked to pick a reward from a group of

pictures depicting various rewards including snacks, taking a walk in the garden, listening to music or time in the sensory room. The token board serves as a visual cue, reminding the children of the reward that they can earn if they control their behavior. A student may earn tokens for “good sitting”, paying attention to the teacher and making eye contact. Each behavior may have a different value. For example, trying to bite the teacher’s hand would cause the student to lose more points compared to the lack of eye contact. The token system is a currency on its own with its own rules and performative techniques. The teachers need to make sure the reward has enough power to reinforce the appropriate behavior. As one teacher told me, “you need to know what motivates them, you need to know what they want”⁵⁶. On the other hand, the teachers are also wary of having the students persevere on the tokens or the rewards. Stereotyped and repetitive behavior, are strictly punished by taking away tokens. One of the major objectives is to “free” the children from the constraints of behavior, particularly repetitive behavior which is one of the defining symptoms of autism. The definition of a repetitive behavior, however, is context dependent. For example, one teacher explained to me how they don’t intervene or stop the child who rocks while listening to music although rocking is considered repetitive behavior. The ultimate objective was normalization. Everything is interpreted within this framework. While inappropriate behavior may be loosely defined, each behavior that would be remotely “repulsive” or “weird” in a social setting results in strict punishment by the removal of tokens. When describing an active child to me, for example, a teacher may observe “the fact that he keeps running around is also

⁵⁶ In addition to having students who persevere on the rewards, the teachers also faced challenges from few students who were not interested in any of the rewards. They could not be pulled into the token economy as nothing worked as a proper reinforcer.

stereotypical behavior”. The students are taught how to wait because they need to wait when they go out shopping with their parents or at school. They need to learn how to keep their mouths closed because it “looks repulsive in a social setting”. A student may also lose tokens for simply scratching his eye or when he expresses rigidity in tonation or rhythm of his speech.

In ABA, the therapy moment can be seen as a situation that is aimed supplying the individual with the ability to self-govern. The therapist and the parent are there to establish the contours of what is considered “appropriate behavior”. There are several strategies to break repetitive behavior: redirection through physical prompting, verbal prompting, or sensory stimulation. They are also rewarded for the absence of unwanted behavior. Students often get tokens for “having a nice quiet mouth and nice hands” or “having a calm body”. If the child exhibits any stimming, the therapist provides a verbal prompt: “show me calm body and calm hands” or reward another child for not engaging in this kind of behavior. If none of these interventions work, they try to redirect behavior by physically diverting his attention. This disciplinary power takes another form with older students. Instead of using physical prompts, teachers simply say, “I see you” in order to divert the student from the stereotypical behavior. The students are encouraged to develop self-discipline and gain control over his behaviors. Behavioral therapy gave the children tools for living, technologies for managing the disease so they can be normalized.

3.4.2. SCIENCE BASED TEACHING

On its website, the TOHUM school is presented as being based in the ABA model because it is known to be the “most effective” method. The intensive educational program of 40 hours a week is obtained from the Princeton Child Institute. TOHUM differentiates itself from other schools as being the “first program to bring different teaching methods with a scientific basis” to Turkey (Tohum Otizm Vakfi 2005). The emphasis on the scientific nature of therapy and the availability of “replicable treatment models” was often emphasized in my interactions with the staff. In the PCDI program, autism intervention therapies based on applied behavior analysis are required to “produce data, not only on the behavior change of people with autism, but also on staff members’ performance, trainers’ and evaluators’ performance, and consumer satisfaction” (McClannahan and Krantz 2008). There was continuous data collection at the school, both on behavior and on the acquisition of skills. Data on students’ progress are reviewed regularly and any progress is recorded as successful teaching on the part of the mentor. Data on performance as well as interobserver reliability provide an essential part of the program.

ABA is based on the assumption that the student practices learning in simplified situations until he develops the ability to learn in a natural environment. Once the objectives are set at the beginning of the semester, the teacher devises an individualized education plan in consultation with the parents, which is used throughout the semester. The number and kind of prompts and reinforcers change until the children master the skill they are working on. The two main technologies used at the school are activity schedules

and script fading. These two technologies are devised to increase spontaneous communication in the students, which is defined as one of the main purposes of the curriculum. The activity schedule is a list that the student puts together at the start of the session. The activities are represented in pictures and are collected in a notebook that the child works through during the session. The activity schedule is designed to improve choice and motivation in the student preparing him for independent study (Siegel 2003). The other technology is the Language Master, which is essentially a card reader that reads keypunched words as the card is passed through a slot in the machine. It is used to develop conversational skills. The child is expected to imitate audiorecorded scripts until the scripts are faded starting by removing the last word. It is meant to teach students how to initiate and continue social interaction (Birkan 2011). The students are encouraged to initiate conversations about their day by repeating the scripts.

These two technologies are reflective of the larger focus on inculcating social habits through repetition. The practice of social interaction involves using others' names, greeting them, and asking each other questions. The only expectation is repetition of the modeled behavior. The idea is to teach rote phrases and behavior, which it is assumed will eventually transform into functional language with enough practice. However, the problem of natural versus robotic behavior hovers over the field of ABA therapies. The idea of "real life" is an organizing principle at the school particularly for older students who will not be educated in a mainstream environment. The teachers emphasize the importance of creating a natural environment for children to learn rather than forcing them to learn at the table. This reflects an ongoing struggle within the ABA circles. One way they have attempted to solve the problem is by adapting incidental teaching, which

they do by excursions especially with older groups where they practice shopping at the market or ordering food at the restaurant.

ABA as envisioned by Lovaas was modeled after parenting. Not only would parents be included in the therapeutic process, but the relationship between the therapist and the individual on the spectrum would be modeled on the parent-child relationship. The application of ABA in Turkey, however, is based on a teacher-student relationship. The therapists are teachers educating the students, teaching them how to excel academically but also how to socialize by simulating the social world at school. The underlying assumption that the teachers were working with is that behavior is an obstacle to academic learning. The objective is to prepare the child to study in an integrated classroom. In order to do this, the teachers need to work on what they describe as disruptive and repetitive behavior but they also need to teach the children how to follow instructions in a group. Both of these can be accomplished only by the physical prompting of the teacher. The teacher, then takes on the role of the parent, in providing *terbiye*, or “moral education” for the child.

3.5. THE CHANGING IMAGES OF AUTISM

Even though most of the Turkish literature on autism presents theories and findings developed in the West, a close reading of these works enables a glimpse at the images of autism that have changed over time in Turkey. This section provides such an analysis based on a close reading of books published by Turkish authors on autism including those by parents and professionals. One significant finding has been the predominance of the

image of the child with exceptional talents. While these representations of special abilities have also been widespread in the West⁵⁷, in Turkish culture such an image has another loaded meaning. Historically, madness has been understood as a form of divine power⁵⁸. The savant skills often associated with autism have strengthened the representation of a child with divine powers. Eracar, a psychologist, argues that when faced with a child who might be exhibiting mild symptoms of autism, doctors often say to the mother: “you are inventing things, this child is clever as a jinn⁵⁹” (Eracar 1995: 2). She then argues that this might in fact be an appropriate depiction since children with autism are just like the jinn who in the Islamic tradition are believed to “have the appearance of human beings but are made of fire and have super-human characteristics” (ibid.). The child on the spectrum can surprise us with his savant skills just like the jinn. One consequence of the emphasis on savant abilities could be the further segregation of children with autism. Instead of pushing for normalization, parents have opted for isolating their children.

Another dominant image has been the child who is lost in his own world and needs to be coaxed out of his shell. This image prevailed particularly during the period that psychogenic theory was understood as the major causal explanation for autism. One of the earliest articles published on autism in 1993, Yörükoğlu describes a child lost in his own world who needs to be coaxed out of this world by the help of professionals and

⁵⁷ For a recent publication on autism and talent see Happe and Frith 2010. For a study on representations of autism in the West, see Draaisma 2009.

⁵⁸ For a discussion of the relationship between “divine madness” in Islamic mysticism and the representations of madness in the Ottoman Empire, see Ayhan 2005.

⁵⁹ This is a common saying in Turkey, *cin gibi*, which is often referred to someone who is exceptionally sharp witted like a jinn.

emphasizes the importance of working on the child's emotional needs (Yörükoğlu 1993). Similarly Tufan describes a “child without emotions” who “has built an unsurpassable fortress around himself for protection” but he argues “these walls are also the child's prison” (Tufan 2002). This image is still prevalent especially among psychologists. For example, a book on autism published in 2000 begins with a poem on the condition of autism (See Appendix 3). Even though the rest of the book focuses on techniques of behavior modification, the organizing metaphor is still that of the child locked up inside who needs to be coaxed out with love, attention and effort.

While the image of the “lost child” has been dominant especially among psychologists, in the field of education the metaphor of “the seed to be nourished through training” has been prevalent. In fact, the most visible foundation on autism is called TOHUM or the seed. Here is how they explain the rationale for this title on their website:

Many seeds are planted for the education of the child with autism. However, only some of these seeds will bloom and grow. If the child with autism receives intensive education (around 40 hrs/week) before the age of five, 40 to 50 percent will adapt to society. So these children develop self-care skills, can live independently in society and can participate in integrated education and are not segregated from their peers. This is why we have named our foundation, TOHUM.

The reason why autism has been incorporated into the jurisdiction of education may have something to do with this moral image. Historically this metaphor of children as seeds that will grow into healthy plant through the help of education is used frequently.

More recently autism is represented as the basis of a new understanding of difference. A book by parent professionals entitled “Can you give me some space? A

book for the normals on autism” advocates that children with special needs are not necessarily impaired but they have different needs. They argue that autism should be understood as a different form of development rather than developmental impairment (Eracar and Onur 1999). They argue that the focus of therapy and education should shift from the individual to the environment and changes need to be made that take into account the sensory needs of these individuals. This radical suggestion is also proof of changing perceptions of disability perceptions of disability. While large-scale parental activism has not taken place in Turkey as I discuss in the following chapter, parents and professionals are beginning to organize to advocate for the recognition of differences. In her book on therapy groups with mothers of children with special needs, Akkök argues that these children are not impaired, but simply different from their peers in some areas (Akkök 2011). Similarly Borazancı-Persson argues that it is difficult to distinguish between autism as behavior and autism as personality hinting at an understanding of autism as identity (Borazancı Persson 2000). In a recent study analyzing the interactions on a Turkish web discussion group focusing on autism, Alat talks about how an identity change occurred in the parents over time. He argues how over time, as parents acquired more information and confidence in the field, they emphasized the importance of “being a special parent of a special child” and began to advocate for their children (Alat 2006).

3.6. CONCLUDING REMARKS

In his discussion of atypical autism, a famous neurologist suggests that these children while exhibiting some major symptoms of autism are otherwise entirely normal. He

argues that such a distinction –between autism and atypical autism- does not result in any meaningful outcome with respect to diagnosis or treatment but carries significance solely for the researcher and the professional (Korkmaz 2000: 20). As I have argued in the last two chapters, experts and parents alike downplayed the importance of the diagnosis. The psychiatrists I interviewed insisted that there were no cultural differences in the way autism exhibited itself and argued that a child with autism would be the same in the United States, in Turkey or in China. However, as I have shown there are in fact significant differences in the detection, diagnosis and treatment of autism triggered by the effects of the welfare state, class structure and the organization of professional jurisdictions, which has crucial outcomes for children on the spectrum.

In this chapter, I have provided an account of the moral trajectory of the middle class child with developmental disorders. The crucial point that needs to be emphasized is that the network of private therapies favors the child with mild behavioral problems, those who can be integrated in mainstream education, those children that can be normalized. Middle class children who are severely disabled receive training at Educational Centers for Autistic Children administered by the Ministry of National Education. They also receive support services either from private therapy centers or the Special Education and Rehabilitation Centers, but their integration to the system does not differ from a child with mental retardation, for example. We do not observe parents and experts engaged in efforts to normalize the child. In this respect, the moral career of the middle class child with mild behavioral problems differs vastly from that of the uncommunicative child with extreme behavioral problems.

The working class child with mild problems, on the other hand, went undiagnosed and remained in the educational system before possibly dropping out. However, according to an expert working in special education, with the shift to integrated education, more children are being referred to the Guidance and Research Centers and receiving educational diagnosis. This could imply different educational outcomes for these children. According to the special education expert, while there are no systematic studies on this issue, early inquiries show that before 2000, teachers would manage these students in the classroom without labeling them. What has changed since then is that labels lead the teachers to give up on these students, often abandoning the educational goals that need to be accomplished during the academic year.

Chapter 4

Civil Society and Claims to Expertise: Autism Advocacy in Turkey

Most of the parents I met during my fieldwork in Turkey were not involved in any advocacy groups. I found this very surprising since a considerable number of the parents I met in the United States were actively advocating for their children either through fund raising activities or through lobbying efforts at parents associations. Turkish parents, on the other hand, portrayed a rather bleak attitude with regards to the power of parental advocacy. According to the mother of a five-year old child with developmental problems, autism “is not something you can work out among mothers”⁶⁰. She went on to explain:

Everyone should be involved in an association but we do not have such habits. We are just an idle crowd. When it is time to talk, everybody has an opinion but when it comes to acting as a group you can’t find anybody. Talking won’t get you anywhere. We have the Autism Platform now but there are no members. I don’t think it will achieve anything.

This attitude toward civic participation is in fact representative of a nationwide outlook on civil society organization in Turkey. Compared to the West, there are a smaller number of organizations and the participation rate is much lower despite the fact that there has been a resurgence of civil society organizations over the last decade. While

⁶⁰ The original phrasing was: *Anneler arasında olacak şey değil.*

there are now a number of non-profit groups actively working in the fields of health, education and poverty, the structure of civic participation has been described as top-down rather than resulting from the mobilization of grassroots organizations.

In this chapter, I provide an analysis of parent associations working in the field of autism in Turkey. I start off with a historical analysis of state – civil society relations paying particular attention to the changing role of non-governmental organizations as a result of the transformations of the welfare state. Then I present a discussion of the importance of parental advocacy in the recognition and dissemination of the diagnostic category of autism in the West and the emergence of the parent-researcher. I will then move on to analyze the rise of a specific form of autism organization that has become dominant in the field. I argue that this organization has been successful in mobilizing resources for the diagnosis and intervention in autism precisely because it could integrate itself into the project of neo-liberal reforms adopted by the state in the last ten years. By doing so, it has differentiated itself from the prototypical parent organization, which had simply served as service providers working with a previous understanding of disability based on mental retardation.

4.1. CHANGING RELATIONS BETWEEN STATE AND SOCIETY

The Marmara Earthquake of 1999 was a crucial moment for the re-organization of state society relations in Turkey. Having caused the greatest destruction in the history of the Turkish Republic, service provision in the aftermath of earthquake was interpreted as a huge failure on the part of the state. Following the disaster, analysts emphasized the

inadequacy of the state in providing social assistance combined with the heroic efforts of civic initiatives. As a political event, the Marmara Earthquake challenged the “strong state” paradigm and exposed the problematic nature of the existing institutional hierarchy (Jalali 2002).

Despite the large-scale involvement of civil society organizations⁶¹ in relief efforts after the earthquake, social analysts have been reluctant to proclaim the increasing power of non-governmental organizations (NGO) as a counter-hegemonic force. It is true that Turkey witnessed a revitalization of civil society organizations. However, this growth was not without problems. For one thing, according to social commentators, civil society didn’t have a structure- it was “less a society than simply thousands of volunteers” (Kubicek 2002a). It was also characterized by a lack of unity and a growing polarization especially between Islamic and secular NGOs (Jacoby and Özerdem 2008; Kubicek 2002a; Kubicek 2002b). In addition, citizens’ claims were framed in a “familial idiom” emphasizing the “state’s paternalistic duties to provide for its citizens”. These claims for social provision were not based on a notion of social citizenship or a rights-based discourse. Instead, the citizens were appealing to the generosity and beneficence of the state in their demands for social provisions. The state, in return, perceived the activities of the NGOs who were stepping in to take over the unfulfilled obligations of the state, as a threat to its image as the “protector of people” (Kale-Lostuvalı 2007: 760).

The earthquake was an important political event that restructured state society relations and had a crucial effect on the development of a path-dependent form of “civic

⁶¹ In this chapter I use the terms civil society organizations and non-governmental organizations (NGO) interchangeably.

regime” in Turkey. This form was characterized by the predominance of volunteerism articulated through a paternalistic relationship with the state and consequently defined by a willingness to take over the activities of the state including social services in health and education, instead of demanding more rights. The emergence of this civic regime could only be possible in the atmosphere of expanding neoliberalism.

Since the early 1990s, the development of civil society has been promoted as the ultimate solution to a wide range of social problems including poverty, human rights violations, and environmental destruction. The remarkable upsurge in civic and organizational activity in 1990s Turkey was received as a sign of increasing democratization of associational life in Turkey. This period was marked by an intense struggle between “the old authoritarian-modernizationist, paternalist state, with its crumbling nationalist and populist legitimation, and a modernist conception of political liberalism and citizenship” (Keyder 1997: 48). Several processes gave rise to this crisis of legitimation and the ensuing expansion of civil society organizations. In their analysis of the emergence of civil society in Turkey, Keyman and İçduygu identify four distinct processes that have been influential in this process: the emergence of alternative modernities, legitimacy crisis of the strong state tradition since the 1980s, the process of European integration and the process of globalization (2003).

The rise of civil society organizations generated much enthusiasm as there was a general understanding that this would democratize state-society relations and transform the “state-centric model of associational life” (Keyman 2005: 44). The rise of new actors such as the Kurds, the Islamists and feminists in the political scene meant the increasing visibility of new political demands. Some commentators believed there was enough

disruptive potential to challenge the existing politics of citizenship and adopt a rights-based discourse and ideals of social citizenship.

The rise of civil society should be analyzed against the backdrop of the neoliberal agenda pushed by the Islamist Justice and Development Party, which came to power in 2002. The ‘conservative democrats’ as they have come to be known have allied with the IMF to cut public spending and privatize public enterprises and natural resources (Tuğal 2007: 21). The transformation of social welfare policies initiated by the new government “reflects a liberal residualism, flavored with social conservative values, that are premised upon the centrality of the family and the significance of communal solidarity” (Buğra and Keyder 2006: 213). This new paradigm is characterized by the retreat of the state from the provision of social services and a shifting of responsibility from the state to the society (Buğra 2008: 239). Social assistance, now re-interpreted as Islamic charity, is identified as beyond the reach of the responsibilities of the state and is delegated to civil society. This approach is particularly stark in the case of poverty alleviation, which is handed over to private benevolence and voluntary initiatives (Buğra 2007). Of particular importance is the coupling of the “autonomy of the subject” and the “responsibility of the subject” in this new form of governmentality.

4.2. AUTISM AS AN ADVOCACY DISORDER

Hacking describes autism as an “advocacy disorder”. He further argues that “militant middle class parents” have been fighting for the recognition of the disorder as well as improvements in educational and social provisions for children on the spectrum and this had an effect on the increased prevalence of autism (Hacking 2006). Unlike most other parental support groups, parents of children on the spectrum have dedicated themselves to not simply raising awareness but also to furthering autism research and evaluating therapies.

An earlier form of parental advocacy, which was crucial in challenging the dominance of the psychiatric profession, was the National Association for Retarded Children (NARC). This organization was built upon local groups of parents who had come together to establish direct services for their children. However, NARC adopted a policy of obtaining these services rather than providing them through adopting a rights based discourse and advocating for legislative and social changes (Roos 1977). By abandoning service provision and concentrating on advocacy, NARC played a crucial role in pushing for deinstitutionalization and normalization. The crucial distinction between various parents groups was based on choosing between becoming a pressure group or a service provider. In this sense, the experience of the British and American autism groups were different. While the American National Association for Autistic Children (NSAC) chose to focus on a national lobbying organization, the British Association was organized primarily as a service provider (Eyal et al. 2010: 168). The strength of NSAC lay in the recognition of the expertise of the parent and the formation of the new actor of parent-activist-therapist-researcher. This was the rise of a new

modality of expertise connecting parents, activists, researchers, clinicians and therapists (Eyal et al. 2010: 170).

Silverman and Brosco emphasize the role of parents in autism research and treatment and report that parents have been actively involved in organizing research funding, constructing clinical networks, proposing new avenues for research, popularizing empirically based therapies and anticipating critical changes in the understanding of autism (2007). Similarly Eyal and Hart argue that parents have won the status of experts on the condition of their children. More than just fighting against the stigma of “bad mothers” disseminated by the psychiatric establishment and for the recognition of their own expertise as parents, the parents challenged the relations of expert knowledge and invented “a new modality of expertise based in a new economy of exchanges between parents, activists, researchers and therapists” (Eyal and Hart 2010).

Parents have been influential in advancing an understanding of autism as a “genetic disorder” and parental organizations have funded genetic research in this area. They have had considerable influence in this area especially after the formation of Autism Genetic Resource Exchange (AGRE) founded by the parent organization Cure Autism Now (CAN). This development facilitate collaborative work on a larger scale but also “CAN made researchers behave in ways that matched the interests of parents” (Silverman 2012: 158). Parental advocacy has been crucial in not just disseminating knowledge but also generating clinical and scientific knowledge on autism. Families have been influential not just in biomedical interventions but also in the creation of a field of autism therapies. As Eyal et al argue it was the particular alliance connecting parents and therapists, a new network of expertise that replaced the crumbling institutional matrix.

The most crucial factor in this process was the inclusion of the parent in the therapeutic process; parents were empowered and accorded a significant amount of expertise (Eyal et al. 2010). Parents have also pushed the boundaries of normal and abnormal through “a new kinship imaginary that positively embraces family members with disabilities” (Rapp and Ginsburg 2011). They have lobbied for changes to accommodate the needs of their children with special needs. In this way, they have been experimenting not with transforming their children but transforming the environment.

4.3. MOBILIZING FOR DISABILITY IN TURKEY

In their report on the disability movement in Turkey, Tufan et al. argue that compared to the other sectors of civil society, non-governmental organizations (NGO) organized around issues of disability have had limited success in influencing public policy and public opinion (2007: 842). Similarly, in her study on disability organizations in İzmir, Yazıcı et al. have found that there are very few organizations serving the community and membership in these associations is very low (2010)⁶². Güçlü also argues that the field is characterized by insufficient dialogue between the state and NGOs, undemocratic decision making processes and the inability to organize for large-scale projects. She claims that the heterogeneity of the organizations with regards to objectives, membership structure and funding mechanisms have resulted in a lack of cooperation across the field.

⁶² There is evidence of strong disability movements in other contexts. For example, in Taiwan, the Parents’ Association for Persons with Intellectual Disabilities, founded in 1992, had thousands of members organized over the country and played a crucial role in shaping disability policy in Taiwan. (Chang 2009)

Their ability to influence legislation and policy remains limited (Güçlü 2007). For example, on the exclusion of disability organizations from legal proceedings, İsmet Gökçek, the president of the Federation of the Orthopedically Disabled, argues

No disabled person attended the commission meetings for the secondary legislation meetings of (the Disability Act). In these meetings for the circulars, sixteen articles regulating how the handicapped people would get medical reports, how they would apply to a hospital, how they would be recruited, or how they would get assistance (were discussed). Do you believe that you can get a sound result if you do not include the handicapped people, the beneficiaries of this legal arrangement? ...All parties are from the state, the government side. ...Why don't the civil society organizations participate? Are we not a party? They had to take us into this commission equally with the state or with the government. (Güçlü 2007: 181)

The field is highly heterogonous, with limited attempts at cooperation across various kinds of organizations as well as with the state. Some have argued that this is reflective of the community at large. This is by no means unique to the Turkish case. Analyzing the emergence of the disability movement in the West, Shakespeare, for example argues that it is hard for the disabled people to recognize themselves as socially oppressed since “(t)he oppression is couched in terms of paternalistic support and charity” (1993: 256).

The uniqueness of the Turkish case derives from the unique history of state society relationship that has been influential in the development of civil society. Karatay argues that historically in the West, charity work in the area of child protection has been

undertaken by organizations independent from the state. In Turkey, however, the development of civil society has been under the influence of the strong state tradition, which means that philanthropic work often had a semi-official character (Karatay 2007: 135). The state is actively involved in the promotion of civic activity that would be strongly supervised by the state. For example, a report on National Mental Health Policy by the Ministry of Health encourages “sustainability of advocacy activities in the field of mental health” (Munir 2006). In addition, a top-down structure could be observed in the organization of grassroots movements in Turkey. A study of three prominent patients’ rights organizations in Turkey reveals that only one has been founded by patients and their families. The others have been founded by healthcare workers, legal scholars and academics (Karlíkaya, Civaner and Hot 2009).

Parental organization for children with special needs dates back to the 1960s (Sucuoğlu 1997). According to Alat, the first generation of these parent organizations aimed to overcome the lack of special education opportunities for children with special needs and to initiate the founding of private day schools. Second generation organizations focused on public awareness campaigns and worked to reduce discrimination (Alat 2006). However, overall participation in these organizations remained limited. Earlier studies report that parental inclusion in special education was limited to exchanging information with the teachers and some involvement in the educational content of the curriculum. Parents were not engaged in any large scale social advocacy on behalf of their children including financial support for the educational institutions, participation in parent advocacy groups and getting involved in the dissemination of knowledge about the disabilities of their children (Sucuoğlu, Küçükler and Kanık 1994; Sucuoğlu 1996). This

finding is not surprising given the very low level of civic participation nationwide. According to a recent report, Turkish citizens remain disconnected from civil society where only 4.5 percent of the population is a member of social civil society organizations (TÜSEV 2011: 21).

4.4. AUTISM ADVOCACY AND CLAIMS TO EXPERTISE

According to a list compiled by the Family Information and Educational Support Program of Anadolu University, there are forty-six civil society organizations that address the rights of children with special needs (ABDEB). Only eleven of these organizations explicitly specify autism in their names. The rest focus mainly on mental retardation and Down syndrome⁶³. In addition to these organizations, I have identified six more organizations, which are members of the Autism Platform (See Appendix 4)⁶⁴. Out of these 17 groups, only 3 were founded before 2000. They were all founded by parents of children on the autism spectrum except for TOHUM. Membership levels in these organizations remain low. While this could partially be explained by the “immaturity” of civil society in Turkey as well as the state’s overbearing influence, there are also reasons

⁶³ Phone interviews with several of these organizations reveal that they often serve a diverse population of children. Most of these organizations are founded in order to provide special education services for children so it would be fair to say that they serve children on the spectrum as well. The crucial difference is that these associations are advocating for more services whereas autism organizations are advocating for the recognition of a new category of disorder and new types of educational arrangements that would benefit children on the spectrum.

⁶⁴ It is possible that there are local parent support groups that have not been organized as associations. Since there is no way of tracking these down, they are not included in the list.

that are unique to the field of autism. As I discussed in previous chapters, middle class parents have been reluctant to organize around a diagnosis. In the absence of sufficient state provisions and given the stigma attached to a diagnosis of autism, autism has become a “disorder without a diagnosis”. This has also prevented advocacy action on a larger scale. Additionally, given the inability of these organizations to effectively function as pressure groups, middle class parents have been reluctant to become members, which further contributed to the existence of autism as a “disorder without a diagnosis”.

Seventeen organizations have recently come together to form a collective called the Autism Platform. The platform is a collective formation advocating for the recognition and rights of people on the spectrum. They lobby for public awareness, anti-discrimination, empirical based educational services and protection of the rights of those on the spectrum through legislation (The Autism Platform). One of their main goals is to ensure full integration for people on the spectrum who “are increasingly excluded from social life and kept at home” (ibid.). Despite this unified front, there is considerable heterogeneity among parents’ associations with respect to their goals and structure. I have identified three types of associations. Some of the organizations, particularly those founded before 2000, reflect an older kind of parent advocacy, one that is similar to those adopted by the traditional organizations for children with mental retardation. These organizations were founded by parents to find immediate short-term solutions to problems they were facing with their children. When their children received the diagnosis of autism, there were inadequate public and private services geared towards children on the spectrum. These children could not attend school, they could not participate in

recreation activities and more significantly parents were desperate about what would happen to their children once they could no longer take care of them. These parents associations, established on the most part by middle class professionals, based in two urban centers Istanbul and Ankara, used mainly private funds to open schools, organize summer camps and to design assisted living projects for their children. These organizations have concentrated mainly on the availability of educational opportunities for their children, lacking a larger nation-wide focus. While parents are actively involved in administrative duties, their participation in educational activities is limited to that of an observer. In these organizations, there is a distinction between the parent and the expert and this difference needs to be respected. One founding member of such an organization, which also runs a special education school, summarized her role:

I create educational environments. I stick to scientifically proven methods so I only work with professionals in the field. ...I leave (the educational) methods to my staff in charge of education. Then who am I? I am not a professional. I am in charge of arranging the (necessary) environment. This is how it should be. There is a new foundation established two years ago. I attended one of its meetings. There was a mother who dared to demonstrate educational methods to the educators! I wouldn't want to be in this situation.

Unlike the West, parental expertise is not recognized in Turkey particularly among these older organizations. This could be explained by the dominance of the psychiatric profession, which has marginalized the importance of parental experience. Parents are reluctant to take on the role of the therapist, let alone the researcher. There is an unshakable trust in the ability of the professionals to address the problems of their

children. This observation provides a stark contrast to the parent organizations in Britain and the United States where parents were either directly involved in the foundation and running of schools or the board of parents supervised the educational programs with heavy intervention.

The second type of organization is established more recently and these are based in small towns and cities across Turkey. They have been founded mostly as a response to the new legislation outlining special education guidelines for children with autism⁶⁵ (Sarı 2000). In 1999, the Ministry of National Education accepted some guidelines in educating children with autism, the Educational Plan for Children with Autism (Otistik Çocuklar Eğitim Projesi). According to these guidelines, children between the ages of 3 to 15 are eligible for services through the newly established Centers of Education for Autistic Children (Otistik Çocuklar Eğitim Merkezi). The purpose of these centers was to prepare students for education in integrated classrooms and provide independent life skills for those children who could not benefit from inclusive education (Aksüt 2001). According to this legislation, the state is responsible for opening an autism classroom, called Center of Education for Autistic Children (Otistik Çocuklar Eğitim Merkezi - OÇEM) if there are three or more children diagnosed with autism in that town. In their

⁶⁵ In Turkey, students need to be evaluated at the Guidance and Research Centers (Rehberlik ve Araştırma Merkezleri) of The General Directorate of Special Education, Guidance and Research Services in order to be allocated to special education classes. Students with special needs including those with visual, hearing, physical disabilities and those with developmental disabilities are often placed in special education schools. Some of these students attend mainstream schools but they receive education in separate or partially separate classrooms. A small number of these students are placed in private institutions and schools founded by voluntary organizations as I have discussed above. In spite of these developments, educational services for children with developmental disabilities are vastly insufficient. (Tohum Otizm Vakfı 2010b)

mission statements, they emphasize the importance of early intervention and intensive education for children on the spectrum. Social services and educational opportunities are concentrated in major urban centers. These organizations work to expand the provision of services to other towns, demanding evaluations services and special education classrooms for children with autism. They also provide information and counseling for parents on a local basis.

The last type of organization is represented by TOHUM, which is a non-profit foundation that derives funds from various sources including individual donors, commercial organizations and political entities like the state and the European Union. Foundations are defined as “legal entities that are formed through the dedication of private resources to public benefit activities” (TÜSEV 2011: 60). Tohum has been effective in developing early diagnosis, early intervention services as well as in lobbying for increased and better special education provision for children on the spectrum. It has provided training for parents, health personnel, and special education teachers. According to its mission statement,

The fundamental objective of TOHUM Autism Foundation is early diagnosis and education of children autism and developmental problems. Within the period of initial five ages, children can learn more than what they can learn throughout their lives. ... (D) iagnosis of autism and starting education before the age of 3 offer a great chance of improvement for the child. What we mean by improvement is the integration of the child to the society at least as much as a dependant individual and ability of the child to continue mainstream education or regular education.

It represents a new kind of organization and distances itself from other organizations and emphasizes that it is not a parent organization. As one of the founders told me:

(When TOHUM was founded,) there were only two active associations and one foundation (working in the field of autism). These associations and foundations were not established to do anything for the benefit of Turkey, but to benefit their children. The foundation had opened a school for their own children. ... There is no foundation that operates like us: nation-wide in increasing awareness of autism, or in translating and adapting diagnostic tools to Turkish, or in conducting projects with the Ministry of Education and the Ministry of Health. I don't know if it is because they don't want to or because they don't have enough funds.

The official stance of TOHUM dismisses the older style parents groups as ineffective self-help groups, which had no lobbying power. The main critique directed against these older groups is their partiality, which in turn has affected their ability to advocate effectively on a larger scale⁶⁶. TOHUM, on the other hand, follows the “social engineering” perspective of the state elite in presuming a societal point of view and promoting early intervention as a “precautionary principle”. Note that this position is similar to that assumed by the psychiatric profession as analyzed earlier.

⁶⁶ The fact that these associations remained local service providers and were not integrated into a larger organization plays a major role in TOHUM's critique of partiality. Both in the West and in other parts of the world, parental activism began as grassroots self-help groups but were later organized as local chapters of national organizations with greater lobbying power. While providing an explanation for why this never took place in Turkey is beyond the scope of this dissertation, one possible reason could be the predominance of a traditional philanthropy outlook rather than an understanding of philanthropy based on social justice (Gökşen 2006).

Unlike the American case, being the parent of a child on the autism spectrum does not enable one to claim expertise in this field. While parents are invited to participate in the educational programs, they are excluded from “administrative” and “scientific” activities, which need to be left to “professionals”⁶⁷. In fact, in the case of this newly founded organization, the inclusion of those who came from outside the field gave the foundation increased legitimacy as opposed to parent-run organizations. According to one of the founders who is the parent of a child with autism on the board:

I represent parents in this organization. Twenty of the twenty-three founding members come from fields other than autism and either give professional support or support the foundation with their names. So parents did not provide any support here but I did that in lieu of parents. Not that I discussed anything with other parents, I just incorporated my observations.

The exclusion of parents from the management provides the foundation the opportunity to assume a more professional character. Given the clientelistic nature of state- civil society relations in Turkey, having a number of prominent industrialists and businesspeople on its board gave the foundation a headstart. This is a point that is often emphasized.

Most of the foundations related with autism in our country have been established by the parents of children with autism with the aim of providing education for their children. However, this is not the case in TOHUM Autism Foundation. Only two of the founders have been part of this

⁶⁷ This situation is not unique to TOHUM. Gökşen notes that all the foundations included in her study on philanthropic activity in Turkey are “expert-driven”. The beneficiaries are not represented and creation of projects and resource allocation are done with minimum input from the beneficiaries (ibid. 84).

foundation due to the developmental problems of their children. Other founders are employers and professionals with good reputation in their engagement areas. Although most of them have their own foundations and are already engaged in the field of education, the founders provided financial and intangible supports just like Ms. Mine and her family due to their sensitivity against autism and after witnessing significant gaps in autism education in Turkey (Tohum Otizm Vakfı 2005).

According to the founder, TOHUM has been successful in implementing large-scale projects because it was able to navigate the complex bureaucratic structure and create pressure on the government for the recognition of autism. It also differs from other organizations in terms of its financial structure. Rather than relying on donations from individuals, they were able to secure funds from domestic and foreign institutions and corporate entities. In addition, they have undertaken fund-raising activities such as an annual autism telethon that airs live on an important television channel. They have partnered with corporate sponsors to fund some of their research activities. They have also collaborated with the Ministry of Health and the Ministry of Education in addition to securing funding from European Union funds for the dissemination of early diagnosis and the training of teachers. The foundation is modeled after American autism associations. There is a Scientific Advisory Board made up of psychiatrists, special education experts and pediatricians in addition to the Board of Trustees and an Executive Board.

TOHUM has been successful precisely because it could translate the interests and form alliances with a wide range of actors including philanthropists, special education specialists, therapists, parents as well as the state. While the older organizations functioned with very restricted notions of autism and education, TOHUM re-defined the field through several strategies. It has taken an active role in “bringing autism to Turkey”

by organizing nation-wide autism screening, lobbying for and implementing early intervention techniques, and founding a school solely based on Applied Behavioral Analysis. The screening project was essential in the formation of the field and the visibility of the diagnosis. During the early years of the organization, the founders were repeatedly told by the authorities that there is no autism in Turkey, the numbers were not there. In response, the foundation takes on a screening study in five cities with support from the European Union. After screening forty five thousand children aged 18 to 36 months, 11.2 percent of all those screened were at risk for autism (Tohum Otizm Vakfi 2008). These numbers were similar to the ones found in the West and they were used in legitimizing the push for more services for children with autism. According to one psychologist who participated in the autism screening project:

Our main purpose was to create a stir in the government. Because they kept saying they had no numbers. (They said) they didn't know how many children were on the spectrum. Our purpose was to (show) the number of children and then (appeal for) special education classes, integrated classrooms, training of more special education teachers.

An important consequence of the screening study has been the training of more than one thousand health care personnel in six cities in the administration of M-CHAT, an autism-screening tool. In this sense, TOHUM works to change autism from a “disorder without a diagnosis” to a widely recognized and visible disability. It could assume this position because the organization does not represent the interests of middle class parents but adopts a universal point of view as represented by its promotion of the campaign of mental hygiene, which was previously taken up by the psychiatric profession.

TOHUM was the only organization that could translate the interests of all the different actors not only by “translating” and “transporting” autism but also by emphasizing education. In fact, the motto of the organization is: Education is the only cure of autism. Particularly the emphasis on education and normalization were crucial in aligning the support of middle class parents. Going back to the discussion on the rise of the civil society in Turkey, one can argue that the conditions of possibility for the rise of such an organization were already in place. On the one hand, the integration process with European Union enabled the flow of funds that could support new forms of associational forms. On the other hand, the discursive power of Europeanization gave legitimacy to the formation of this new kind of organization by emphasizing the importance of the role of civic initiative in the provision of social services.

The professional organization of TOHUM combined with the ambitious project of establishing a private school for only a select number of students that can provide forty hours of behavioral education per week have led others to label it as “elitist”. In its school, Tohum provides intensive education based on Applied Behavioral Analysis (ABA). They have adopted the curriculum from Princeton Child Development Institute (PCDI), whose mission is “to provide effective, science-based interventions for children and adults with autism and, through research and dissemination, to extend treatment resources to people with autism, both nationally and internationally”(PCDI). This emphasis on the “scientific method” is very significant, as I have argued in the previous chapter. Also significant is the success rate of the PCDI system in placing students in integrated classrooms. This is the main struggle for parents and civil society organizations in Turkey – increasing the availability and effectiveness of intensive early

education and inclusive education for their children. The PCDI connection is also used for further legitimacy as Tohum claims to provide a true replica of the “Western” method of education. In fact, they have been influential in bringing the Applied Behavioral Analysis (ABA) method to Turkey. They offer training sessions for special education teachers and other professionals working with children on the spectrum. In the absence of any systematic training on autism, this has definitely been an important contribution but it has also created a new community of therapists who follow the teachings of TOHUM and apply the ABA system. While previously therapists would use an amalgam of various methods including behavioral, occupational and play therapy, the promotion of ABA is increasingly deepening the divides within the field of therapies. As one professional put it, “more than ever therapists are being asked to choose sides”. The strict adherence to the behavioral paradigm and Tohum’s dismissal of other therapies such as Picture Exchange Communication System (PECS) or TEACCH Autism Program create discontent among some therapist who have been working with these methods. One therapist complained about the rigidity of the Tohum program:

ABA is increasingly being used with children on the autism spectrum as an effective method throughout the world but this doesn’t mean that ABA benefits every child one hundred percent and helps them progress. Sticking do firmly to one method is against my logic because we don’t even know the cause of autism. Not every child is suitable for ABA. Who can decide (which method is beneficial for the child)? You might believe in this method one hundred percent, you might present empirical evidence and support your views with scientific proof but we are dealing with something else here because we don’t know the cause (of autism). There is no cure.

Everything is in the air. ...Maybe even if you work with the child for forty hours, it still won't be effective.

According to a parent advocate, previously therapists would not identify themselves with any particular therapy. According to her, “they would not advertise themselves as applying floortime for fear of losing other clients and instead would present themselves simply as ‘autism educators’”. This is beginning to change as parents are increasingly demanding specific therapies either floortime or behavioral therapy.

More significantly the success of the foundation should be analyzed within the recent neo-liberal transformation of the Turkish state. By assuming responsibility for many services that would have been undertaken by the state under a welfare regime, TOHUM has filled the gap, which emerged as a result of the retreat of the state. In addition, the trainings provided by the foundation to teachers and therapists provide an important resource as the state begins to support integrated education.

4.5. CONCLUDING REMARKS

The role of the civil society organizations has mostly been limited to various forms of charity work. There has also been a visible split in the organizations that work with children on the autism spectrum. While older forms of associations focus on securing benefits for the children of the families that have founded the organization, new associations are pushing for universal benefits and lobbying for the changes in the field of special education. However, in all these organizational forms, parents are seen as suspect

and viewed as unable to effectively train their children or lobby for their children. In this respect, the field differs from its Western counterparts particularly because parental expertise is not valorized.

The exclusion of parents may have important consequences for the development of the field in the future. This will intensify the fissures between the grassroots organization of parents in the periphery and the expert driven formations in urban centers. The lack of a larger social mobilization hinders the development of parental organizations into more effective pressure groups. The inclusion of parents in this process has the potential to transform this type of organization from an elite lobby oriented interest group to a national advocacy network similar to those observed in other parts of the world.

Conclusion

One of the most significant ways in which autism has become part of public consciousness in Turkey was through a widespread media campaign for autism awareness in 2005 organized by the newly founded TOHUM Autism Foundation. The television ads showed a young boy sitting in front of a washing machine and fixatedly watching it rotate while the voice over explained the symptoms of autism:

If your child exhibits stereotyped movements like hand flapping and rocking, does not respond to his name; if there is a significant delay in his speech development, if he doesn't play with his peers; if he watches things that spin for hours, he might have autism. Education is the only cure. In Turkey, over 100,000 of our children are in need of education. With early diagnosis and education, they can, just like Doğuş, go to school, play with their friends.

Over the years, this ad became a significant symbol of autism as parents repeatedly referred to it while trying to understand what was wrong with their children. Almost all of the parents mentioned this ad while talking about seeking help for their child. This was also the starting point of this study. Inspired by this wide scale campaign, my initial hypothesis was that the field of Turkish mental health was increasingly being Americanized under the influence of the DSM with warnings of an “autism epidemic”

and parents advocating for legislative changes and educational opportunities for their children. A closer look, however, revealed that what appears as a global diffusion of autism discourses and practices in fact involves a selective adaptation and translation to local conditions. In Turkey, this process is determined by a particular history of state-society relations, of the psychiatric profession, of the lack of deinstitutionalization as well as the neoliberal transformation of the welfare state. A combination of these dynamics have resulted in the marginalization of the autism diagnosis as represented by the number of children diagnosed with autism which do not come close to the rates found in the West as well as the exclusion of parents from the field resulting in a situation I have called autism as a “disorder without a diagnosis”.

These findings led me to the conclusion that the diffusion paradigm remains insufficient to understand the transposition of autism to the Turkish context. Neoinstitutionalists understand the global diffusion process as one of isomorphism or increasing structural similarity among organizations. The underlying process is understood to be a decoupling between form and content whereby institutional convergence is sustained through the adoption of formal structural traits that conform to institutional cultural beliefs primarily as a means to gain legitimacy (Meyer and Rowan 1977). This theoretical decoupling of structure from activity results in an overemphasis on categories and institutional structures rather than the process of the reordering of ideas, practices and relations of expertise. The present study addresses this deficit in the diffusion paradigm by analyzing the practices of translation that ensure the “liquidity” of a diagnostic category. Combining historic and ethnographic data, I suggest that in order to understand the process of adaptation and translation, we need to follow the actors and

ideas as new alliances are formed and new networks are established. In the Turkish context, autism emerged as a “disorder without a diagnosis” because the alliance between middle class parents and therapists was based on a dismissal of the diagnosis. This study has shifted the focus to a study of practices of diagnoses as well as an examination of treatment regimes. It has emphasized the conflicts, negotiations and alliances that are taking place as children are increasingly put under surveillance.

Additionally, existing studies on the diffusion of mental health categories have emphasized standardization and globalization by focusing on the role that the Diagnostic and Statistical Manual of Mental Disorders (DSM) plays in the United States. However, not only does diffusion trigger a new set of institutional changes as it enters new locales (Fourcade 2006) but what makes an element of diffusion relevant in one context may be lacking in other contexts. Hence, the working of the DSM was dependent on the particular form of welfare state, strong patient advocacy movements, the specific role played by insurance companies in the West. The institutional conditions in Turkey were vastly different from those observed in the West, which led to variations in the object of diffusion resulting in divergent outcomes.

This dissertation has investigated the ways in which developmental delays are detected, classified and treated in the Turkish context. My findings suggest that there is a split moral career of the child presenting with developmental problems in Turkey with divergent paths to referral, diagnosis, treatment and prognosis. Parents of lower class children seek help later compared to other groups, missing the critical years of intervention. Hence, these children tend to exhibit more serious behavioral problems. Parents are referred to state hospitals where they are more likely to get a diagnosis of

autism and prescription for multiple medications to manage the disease leading to what I have called “managed confinement”. Middle class families, on the other hand, actively avoid the diagnosis given the inadequacy of state services for children on the spectrum. They opt for the private market and intensive behavioral intervention, which may eventually help their children “lose the diagnosis” altogether and participate in mainstream or integrated education classrooms. This has been possible because middle class parents have formed an alliance with the psychologists and educators around autism as a “disorder without a diagnosis”. Of course middle class children with severe symptoms still need to navigate the system of medical diagnoses, educational diagnoses and special education. However, anecdotal evidence suggests that these families opt for a diagnosis of mental retardation particularly because it enables their children longer years of schooling. Lower class children with mild symptoms on the other hand, are rarely detected by the system. While there are no studies on this subject, special education experts suggest a correlation between dropping out of school and undetected disabilities.

Of particular importance has been the history of the psychiatric profession in the formation of these divergent trajectories. In the absence of deinstitutionalization, the psychiatric profession did not face any real challenges regarding its claims to expertise. However, the transformation of the welfare state had a crucial impact on the organization of mental health care. With the growth of private therapy centers, staffed by psychologists and special education experts, the psychiatrists lost their gatekeeper positions in access to mental health care. The end result was a jurisdictional settlement between the two professions, which fueled the split in the two developmental pathways described above.

What we observe in the Turkish case is a split between the institution (public university hospitals) which more or less function in the paradigm of mental retardation and cater to lower class parents and the private clinic where there is considerable flexibility as to the nature of the disability as well as the method of intervention and these cater to middle class parents. This has meant that the psychiatric profession did not face a challenge either from the parents or from other neighboring disciplines. There has been a jurisdictional settlement between psychiatrists and psychologists/educators who do not want to be seen as encroaching on the jurisdiction of psychiatry and want to maximize flexibility in admission policies and thus become active partners in the formation of a “disorder without a diagnosis”.

This study has shown that professional struggles, the inability of parents to effectively challenge the dominance of the psychiatric profession combined with the lack of a history of deinstitutionalization have been influential in the specific ways in which autism is diagnosed and treated in Turkey. In doing so, it has highlighted the asymmetries present in the transcultural flows of biomedical knowledge. A significant contribution has been the finding that lower class children are more likely to get diagnosed. While the idea of a spectrum has been influential in the strengthening of autism as a diagnostic category in the West, in Turkey middle class parents ally with therapists to take the spectrum apart and opt out of the diagnosis altogether.

The present study contributes to our understanding of the social life of clinical diagnoses. While there is a growing interest in social studies of health in Turkey, none of these studies have focused on the field of mental health. Existing studies have either concentrated solely on macro transformations in the health sector as they relate to the

transformation of the welfare state or they have sought to uncover patient narratives. The present study aims to contribute to this growing literature by bridging these two approaches through a focus on relations of expertise. It does this by analyzing how the increasing privatization of mental health care triggered by the transformations in welfare state intensified jurisdictional struggles and led to the formation of new alliances, which has led to the reorganization of the relations of expertise. While the monopoly of psychiatry was challenged by the influx of other experts and civil society organizations, the settlement involved a division of clientele as described above. This study also draws attention to the role of parents as they negotiate their way in this new system.

A number of important limitations need to be considered. The study has focused on the autism community in Istanbul. Integrating cases from other parts of the country, particularly the periphery, would have greatly enriched the existing data. Taking into consideration that there are only eight other towns with pediatric psychiatry departments, I would expect to find a considerable variation in the detection and treatment of autism in other settings. In addition, a deeper analysis of parents' mobilization in the countryside would also provide a better insight into the organization and transformation of the field of autism activism in Turkey. Given the scarcity of epidemiological and statistical data on autism and other developmental disorders in Turkey, this study had to rely chiefly on qualitative evidence. There is an urgent need to collect reliable data on the diagnostic processes in different parts of the country as well as on the developmental trajectories of these children.

In addition, more work needs to be done in order to investigate the role of religious healing as an alternative form of therapy in autism spectrum disorders. Parents

have frequently mentioned these therapies in their narratives and initial observations suggest that the two treatment regimes, Western biomedical and Islamic, co-exist as parents seek help for their children from multiple sources. Future studies could assess how families balance these two modalities and how they negotiate the dominant biomedical outlook with that of the Islamic one.

As I mentioned in earlier chapters, there are other forms of therapeutic interventions in the field of autism, most of which are dismissed by experts as being unscientific. The number of parents who employ these biologically based methods, which include chelation, vitamins, diets, hormone therapy and detoxification are growing in Turkey. This behavior opens up crucial lines of inquiry particularly as parents continue to frequent these types of therapy centers despite the fact that the dominant biomedical discourse is against such interventions.

The present study has exposed several questions in need of further exploration. Future studies may explore the rise of the Attention Deficit and Hyperactivity Disorder (ADHD) as a comparative case. Initial observations suggest that middle class parents are more likely to embrace a diagnosis of ADHD while parental advocacy in this field is almost nonexistent. This case could provide an opportunity to further explore the relations of expertise in Turkey.

Further research is also needed to determine the impact of the transformations in the field of special education. The recent adoption of a policy of integrated education, whereby students with special needs are included in mainstream classrooms with some additional educational support, is already creating tensions among teachers, administrators, parents and families of children with special needs. The number of

primary and secondary school students in integrated classrooms has more than doubled from 31,049 in 2003 to 76,204 in 2010 (Tohum Otizm Vakfi 2011). This policy will no doubt have significant implications for the reorganization of networks of expertise in Turkey as more families need to go through the bureaucratic channels to get the appropriate services for their children. More significantly, there are still a large number of children who are not placed in integrated education programs due to the discriminatory policies of schools. Some families have begun to take legal action against these schools which will have further implications for the field.

POLICY IMPLICATIONS

If the debate is to be moved forward, further social scientific investigations of the recognition, diagnosis and treatment of mental and developmental problems in Turkey are urgently needed. This necessity has also become evident during my fieldwork experience. One of the difficulties I encountered in the field was general skepticism toward social scientific studies especially from clinical workers. They were unfamiliar with the methodology as well as the theoretical constructs of sociological work. I believe studies such as this one will remedy this situation by contributing to a social scientific understanding of the clinical encounter. However, popular writings in this area need to be encouraged. Additionally, the findings of this study, mainly the class dimension of the diagnostic process, will be beneficial for practitioners working in the field of autism. By emphasizing the structural inequalities in access to special education and other

therapeutic interventions, the present study draws attention to the urgency of taking actions to remediate the situation.

The problems concerning the development of a strong advocacy movement may give us clues on how to strengthen the role of parents in the areas of disability and education. Of particular importance is the need to create spaces for the empowerment of families and children. The local groups mobilizing in the countryside to demand more services for their children could be the start of a new form of advocacy. In addition, the creation of autism only classrooms and the expansion of the rehabilitation centers to the periphery suggests that parents of children on the spectrum are meeting other parents at a much higher rate than before. This proximity could be channeled into a more effective form of mobilization.

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Appendix One

Information Letter for the Participants

I am a student of Sociology at Columbia University. My name is Emine Onculer. I am conducting a study on autism in the guidance of my advisor Professor Gil Eyal. Our research is on how autism spectrum disorders are understood in society. We are especially interested in how experts, families and children give meaning to autism. We would appreciate your participation in this study.

Our purpose is to better understand the organizational structure of autism associations and to investigate how parents partner with experts in this field. Your participation in this study is voluntary. There are two ways in which you can participate. You may participate in any, both or none of these capacities. All are optional. Please indicate verbally if you consent to participate.

1. As part of this study Emine Onculer would like to observe and take notes during therapy sessions or diagnostic sessions with your child. Do you give consent?

Yes

No

2. Emine Onculer would like to ask you some questions about your experiences with autism.

Yes

No

We do not anticipate the study will present any risk to you other than the potential inconvenience of having an observer in the room. While there may be no immediate benefit to you, we anticipate the results of this study will help us improve collaborations between professionals, parents, and individuals with autism. You may choose not to participate in this research. If you so choose, no information will be collected or recorder about you. If you decide to participate, you are free to withdraw from the study at any time. In this case, all information collected about you or your child will be destroyed. The information we collect through observation will be confidential and will not include any identifying information on you to anyone that could identify you. All the data will be kept in a locked cabinet.

If you have any questions about this research study, you should contact Emine Onculer at 530-614-7410 or by email at Onculer@gmail.com.

For questions about your rights as a research subject, you should contact the Institutional Review Board of Columbia University by phone at +001 212- 851-7040 or by e-mail at askirb@columbia.edu.

Appendix Two

Diagnostic Criteria for Autism in DSM-IV-TR

Diagnostic criteria for 299.00 Autistic Disorder:

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

- (1) qualitative impairment in social interaction, as manifested by at least two of the following:
 - (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (b) failure to develop peer relationships appropriate to developmental level
 - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - (d) lack of social or emotional reciprocity
- (2) qualitative impairments in communication as manifested by at least one of the following:
 - (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

- (c) stereotyped and repetitive use of language or idiosyncratic language
- (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
- (3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - (d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Source: Diagnostic and Statistical Manual of Mental Disorders, 4th ed. 2000.

Appendix Three Images of Autism: Poem

MY SILENCE

My mind is empty,
My ideas are floating,
And my words are often meaningless.

Who is my mother, who is my father,
I often can't put my mind together,
This is very disturbing.

I am often angry,
And often I am cross,
I make others unhappy with the unknowns in my behaviors.

Please help me,
I am not impenetrable,
With some love, attention and effort,
I can succeed in many things.

Source: Darıca, Gümüşçü and Pişkin 2000

Appendix Four

List of Autism Advocacy Groups in Turkey

	Name of Organization	Date founded	Founders	Activities
1	Türkiye Otistiklere Destek ve Eğitim Vakfı (TODEV)	1991	Parents of children on the autism spectrum	Running their own Rehabilitation and Therapy Center, Organizing Autism Education Days, Planning a residential institution for individuals on the spectrum
2	İlgi Otistik Çocukları Koruma Derneği	1993	Parents of children on the autism spectrum	Running their own Rehabilitation Center, Running a Special Education School for ages 0-14, Organizing conferences, family counseling, publishing on autism
3	Otistikler Derneği (Istanbul)	1996	Parent who is also a psychologist working with children with special needs	Organizing autism integration camps to bring neurotypicals and individuals with autism together, planning for an autism village

4	Otistik Çocukları Koruma ve Yönlendirme Derneği (ODER) (Izmir)	2000	Parents of children on the autism spectrum but members include professionals	Advocating for integrated education, providing training for teachers
5	Otistik Çocukları Koruma ve Eğitim Derneği (Mersin)	2001	Parents of children on the autism spectrum	Raising awareness, fund raising for special education, family counseling, legal interventions
6	Otizmle Mücadele Eden Aileler Derneği (OMAD)	2002	Initially web-based support group for families, professionals, teachers	Raising awareness, disseminating information through the listserv, music and sports activities for children
7	Bursa Otistik Çocuklar Eğitim ve Dayanışma Derneği	2002	Parents of children on the autism spectrum	Raising awareness
8	TOHUM Otizm Vakfı	2003	Most are philanthropists, includes some parents	Running their own autism school and rehabilitation services, Early diagnosis, Teacher training, Family counseling, Prevalence studies, Supporting scientific research, Fund raising, Lobbying for children's rights

9	Tekirdağ Otistik Çocukları Koruma Derneği (TOÇOKDER)	2005	Parents of children on the autism spectrum	Providing possibilities for integrated education though summer camps
10	Otistik Çocukları Eğitim ve Yaşatma Derneği (OÇEYDER) Edirne	2006	Parents of children on the autism spectrum	Fund raising for special education classes, raising awareness
11	Ankara Otistik Bireyler Derneği (ANOBDER)	2007	Parents of children on the autism spectrum	Raising awareness, family counseling, organizing sports activities for children
12	Asperger Sendromu ve Otizmle Hayat Derneği (ASPERDER)	2008	Parents of children with Asperger's syndrome	Raising awareness, fighting against discrimination
13	Kocaeli Otistik Çocuklar Derneği (KOÇ-DER)	2009	Parents of children on the autism spectrum	Raising awareness, lobbying for the provision of special education services
14	Konya Otistik Çocuklar ve Aileleri Yardımlaşma Derneği(KOÇAYDER)	2009	Parents of children on the autism spectrum	Raising awareness, family counseling
15	Antalya Otistik Bireyler Spor Kulübü Derneği (ANTOBDER)	2009	Parents of children on the autism spectrum	Raising awareness
16	Rize Otizmle Mücadele ve Eğitim Derneği	2009	Parents of children on the autism spectrum	Raising awareness, family counseling
17	Otizimli Bireyleri Destekleme Derneği	2011	Parents of children on the autism spectrum	Working on special education and

integrated
education
projects,
trainings for
teachers